THE UNIVERSITY *of* EDINBURGH

Parent Carers of Adults with Brain Injury

A Thesis Portfolio

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University of Edinburgh
Doctorate in Clinical Psychology
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ABSTRACT: THESIS PORTFOLIO

Consequences of acquired brain injury (ABI) can be life long and complex. The majority of those who sustain an ABI are cared for by family members. Many are young adults who are cared for by parents. A systematic review highlighted that there is little in the way of research that focused on the experience of parent caregivers, particularly in the traumatic brain injury (TBI) population and in the early days of caregiving post discharge from hospital.

Method

A qualitative design using Interpretative Phenomenological Analysis (IPA) was used. Six participants were recruited; three from the NHS and three from Headway.

Results

Four superordinate themes emerged: carrying on with the parenting role; barriers to caregiving; factors that engender mastery; and the psychological, physical and social impact on parents.

Conclusion

The early weeks at home following discharge from hospital are exciting but exhausting and parents were ill-prepared to meet some of the challenges. Parents wanted more TBI specific services for their family members and themselves. Some experienced difficult emotions during the first few weeks at home and so there is a need for regular, on-going input that starts before discharge from hospital. This has relevance for professionals as parents should be involved in the care and decision making from the acute stage onwards as they will be the people assuming responsibility on discharge from hospital. They should be assessed early on to see what psychological or practical support must be in place before their family member leaves hospital.

Introduction to thesis portfolio

Overview

Every year, more that 150 000 people in the United Kingdom suffer a brain injury and are admitted to hospital (Shoumitro & Burns, 2007). Many of these people will continue to need care after discharge from hospital and it is often family members or partners who provide that support (Shoumitro & Burns, 2007; Nalder, Fleming, Cornwell & Foster, 2012). Survivors of TBI often display behavioural and cognitive problems particularly with regards to attention, memory, executive functioning and processing speed (Wilson, 1999), as well as depression, anxiety, increased aggression and mood swings (Ponsford & Schoenberger, 2010).

Caring for someone who experiences some of these problems can be hugely demanding (Nalder et al., 2012) and can lead to the carers themselves becoming unwell. Carers may experience mental health problems and the whole family functioning can be affected (Verhaeghe, Defloor, & Grypdonck, 2005). Although they play a vital part in helping the brain injured person throughout the rehabilitation process, they are often un-prepared for this demanding, long-term task (Man, 2002). They have to cope with significant emotional, physical and cognitive changes in their relative and also have to come to terms with the huge impact on their own social and vocational lives (Gillen, Tennen, Affleck & Steinpreis, 1998; Minnes, Graffi, Nolte, Carlson & Harrick, 2002).

Acquired brain injury (ABI) has been defined as an inclusive category that is applied to any acute, rapid onset brain injury (Royal College of Physicians & British of Rehabilitation Medicine, 2003). ABI therefore includes TBI, vascular accident, cerebral anoxia, other toxic or metabolic insults and infection.

TBI has been defined by the Scottish Intercollegiate Guidelines Network (SIGN, 2013) as follows:

"Traumatic brain injury may be defined as a traumatically induced structural injury and/or physiological disruption of brain function as a result of an external force that is indicated by new onset or worsening of at least one of the following clinical signs, immediately following the event:

- any period of loss of or a decreased level of consciousness
- any loss of memory for events immediately before or after the injury
- any alteration in mental state at the time of the injury (confusion, disorientation, slowed thinking, etc)
- neurological deficits (weakness, loss of balance, change in vision, praxis, paresis/plegia, sensory loss, aphasia, etc) that may or may not be transient, or
- intracranial lesion." (p2).

The SIGN guidelines (2013) also recommended that family and carers should be provided with access to ongoing support once the patient with brain injury is living within the community.

The type of support is likely to be more relevant if more is understood about the experience of caring from the perspectives of those who are living through the experience. A large number of adults with ABI are cared for by parents on their discharge from hospital (Perlesz, Kinsella & Crowe, 2000). There is little research on the experience of younger adults with TBI and their parent caregivers.

The research portfolio

This aim of this portfolio is to explore the experience of parents who care for an adult child with TBI.

The first part consists of a systematic review journal article. Qualitative literature was reviewed in order to assess and synthesise the knowledge base on parents' experience of caring for adults with ABI. The results highlight that there is a relatively small amount of qualitative research published on the parent carer giver population. Results showed that although parents assumed the responsibility, without question, of care after discharge from hospital, there was little in the way of preparation for that role. Parents faced many challenges that had a negative impact on their personal autonomy, physical and mental health and relationships within the family. There were also positive aspects to care giving as well.

The second part of the portfolio contains the empirical research project. The systematic review had highlighted a gap in the research literature concerning parent carers of adult children who had sustained a TBI. Also, much of the research had covered a very wide time range; from a few months to twenty years. Turner, Fleming, Ownsworth and Cornwell (2011) highlighted the importance of the hospital to home transition phase as it is often the time that patients begin to have a greater understanding of the impact of their injuries, and when carers have to cope out with the sheltered environment of the hospital.

Interpretative Phenomenological Analysis (IPA) was chosen as the method to explore the experience of parents as they tried to make sense of their new circumstances. The

research project produced four superordinate themes which give a sense of the experience of six parents.

At the end of the empirical study there is a chapter that discusses the methodology and quality appraisal in more detail that could not be included in the journal articles. Finally, there is a reflective section on the research process.

Note regarding formatting

The two journal articles were written in line with author guidelines for two different publications; the systematic review in accordance with "*Psychology and Health*" and the empirical study in accordance with "*Neuropsychological Rehabilitation*" (See Appendix A and B for copies of the guidelines).

PART I

SYSTEMATIC REVIEW

Title: How do parents experience care-giving for their adult children after Acquired Brain Injury: A Systematic Review of the qualitative literature.

(Word count excluding references 7230)

(This systematic review is written in the style accepted by "Psychology and Health".)

Abstract

Acquired brain injury (ABI) is a leading cause of death and disability. For those who survive, consequences can be serious and life long. Many of those injured are young adults who often are cared for by family members on their discharge from hospital. Parents make up a considerable number of those caregivers and can experience a variety of stresses, ill health and burden. A literature search was carried out in order to assess and synthesise the quality and findings of qualitative studies that addressed the topic of parents caring for young adults who had sustained an ABI. Eight studies met the inclusion criteria. Insights into the experience of care giving were presented in a meta synthesis which produced four broad and interrelated themes: Emotional turmoil of parents; Centrality of caring for their adult child; Protection/promoting independence, and the Effects on family relationships. These findings should inform clinical practice in caring for caregivers who assume the demanding responsibility of care. Clinical implications, methodological shortcomings and ideas for future research are included.

Keywords: Acquired brain injury; caregivers; parents; experiences; perceptions.

(Word count 178)

Introduction

The Royal College of Physicians & British Society of Rehabilitation Medicine (RCP & BSRM, 2003) defines acquired brain injury (ABI) as an inclusive category of rapid onset brain injury of any cause; which includes trauma, cerebral anoxia, vascular accident or other toxic or metabolic insults and infection. According to these guidelines (RCP & BSRM, 2003) accidents resulting in head injuries that require hospitalisation in the UK occur at an annual rate of 275/100,000. Predicting the outcome of those who have suffered an ABI can prove to be difficult, as some patients who have suffered a severe injury can be known to make a good recovery, whilst others in the mild range can experience long lasting and catastrophic effects (RCP & BSRM., 2003, p.8). Due to the range of conditions that are considered to be an ABI, it is difficult to assess the prevalence of ABI.

The responsibility of caring for a family member with ABI usually falls to family members, especially spouses or parents (Perlez, Kinsella & Crowe, 1999; Machamer, 2002). Injuries occur without warning and family members are not prepared for such a traumatic incident (Rotondi, Sinkule, Balzer, Harris & Moldovan, 2007; Norup, Welling, Qvist, Siert & Mortensen, 2012). Caregivers can experience depression, grief, and lower quality of life (Riley, 2007; Norup, et al., 2012; Martin, 2012). Research has shown that caregivers' health, subjective burden and stress can have a major impact on their ability to provide care. It has also been shown that low subjective burden and stress in caregivers has a positive effect on the person receiving care (Rotondi et al., 2007). These authors highlighted the importance of supporting caregivers, because of the close relationship between the caregiver's well being and

that of the care receiver, and that support for caregivers should be an integral part of brain injury rehabilitation practice.

Previous systematic reviews have examined the experience of caring for individuals affected by ABI (Greenwood, Mackenzie, Cloud & Wilson, 2009; Martin, 2012; Ennis, Rosenbloom, Canzian & Toplovec-Vranic, 2013). Greenwood et al. (2009) carried out a review of qualitative literature exploring the experience of caring for stroke survivors. Findings indicated that caregivers experienced difficulties regarding unanswered questions about brain injury in general. In particular they were concerned with their family member's prognosis, their lack of training and unaddressed emotional needs. Greenwood et al. (2009) reported that the qualitative methods used in their reviewed papers allowed for the inclusion of positive aspects of caring that may otherwise have been overlooked. Greenwood et al. (2009) also recommended that future research should look to explore divergences as well as convergences in caregivers' experience.

Martin (2012) reviewed qualitative literature on the experience of care giving post TBI. Only five papers matched the inclusion criteria and they were of variable quality. The findings reported that caregivers experience a range of complex needs such as worries about the future for themselves and the injured person, their own lack of autonomy and their efforts to foster independence in the injured person. Carers also spoke of their developing expertise in the role of caregiver. Professional support was appreciated but there were variable experiences of the availability of services when it was available.

The review of quantitative research on TBI caregivers by Ennis et al. (2013) examined the experience of depression and anxiety in both parental and spousal caregivers post TBI. Twenty-four papers, of varying quality, were included in this review. Ennis et al. (2013) critiqued these papers according to unclear aims, poor descriptions of samples and a lack of consensus around measurement. Overall, the review suggested that psychological distress is similarly high, whether the caregiver is a parent or a spouse of the brain injured person. Ennis et al. (2013) stated that it is important to understand more about the different pressures on different caregiver groups when considering rehabilitation options. In particular, ABI can change lives forever (Marsh, Kersel, Havill & Sleigh, 2002) and it is important to understand the impact on the primary care giver. Usually, this is a parent and likely to be the mother (Marsh et al., 2002).

As far as the author is aware, there has been no systematic review of the qualitative literature on the experience of parental caregivers of adults with ABI. There have been reviews published on mixed carer groups or comparing the experience of two types of carer relationship or spouses caring for stroke patients. The purpose of the current review is to systematically explore the experience of parental caregivers of adult children who have sustained an ABI, because it is a relatively under researched area.

The research question for the review is, "How do parents experience care-giving for their adult children after Acquired Brain Injury?" The first part of the review consists of a literature search for relevant papers that address the research question and a critical appraisal of their methodological quality**.** The second part consists of a

meta-synthesis of the findings. Clinical implications and ideas for future research are discussed.

Search strategy

The following electronic data bases were searched in April 2014; EMBASE, Medline, PsycINFO, PubMed and CINAHL. The search terms used were the following key words in combination: ("Traumatic brain injury" OR "brain injury" OR "TBI" OR "acquired brain injury" OR "stroke" OR "cerebrovascular accident") AND ("care giver" OR "caregiver burden" OR "parent" OR "mother" OR "father" OR "family") AND ("qualitative" OR "qualitative study" OR "qualitative research" OR "experience" OR "perspective" OR "perceptions" OR "grounded theory").

In addition, reference lists of studies and reviews were hand searched as well as relevant journals including "Neuropsychological Rehabilitation", "Archives of Clinical Neuropsychology", "Clinical Rehabilitation", "Journal of Rehabilitation Medicine", "Brain Injury", "Psychology and Health", "Health Psychology Review" and "Disability and Rehabilitation." One article was found on Google Scholar. Attempts were made to contact the authors of significant papers. Two authors responded but this did not lead to any further studies. Theses, dissertations and other 'grey literature' were not included in the current review as the purpose was to review studies published in peer – reviewed journals.

A total of 584 papers were identified. The abstracts were screened for relevance to the aims of the review. This led to the exclusion of 444 papers. The full texts of 140 papers were obtained and read in full to see if they satisfied the inclusion criteria. Of

these, 120 were excluded. De-duplication removed 13 papers. Eight papers were left which were included in the current review (Appendix C, search strategy). The literature search is shown in the flow chart below (Figure 1):

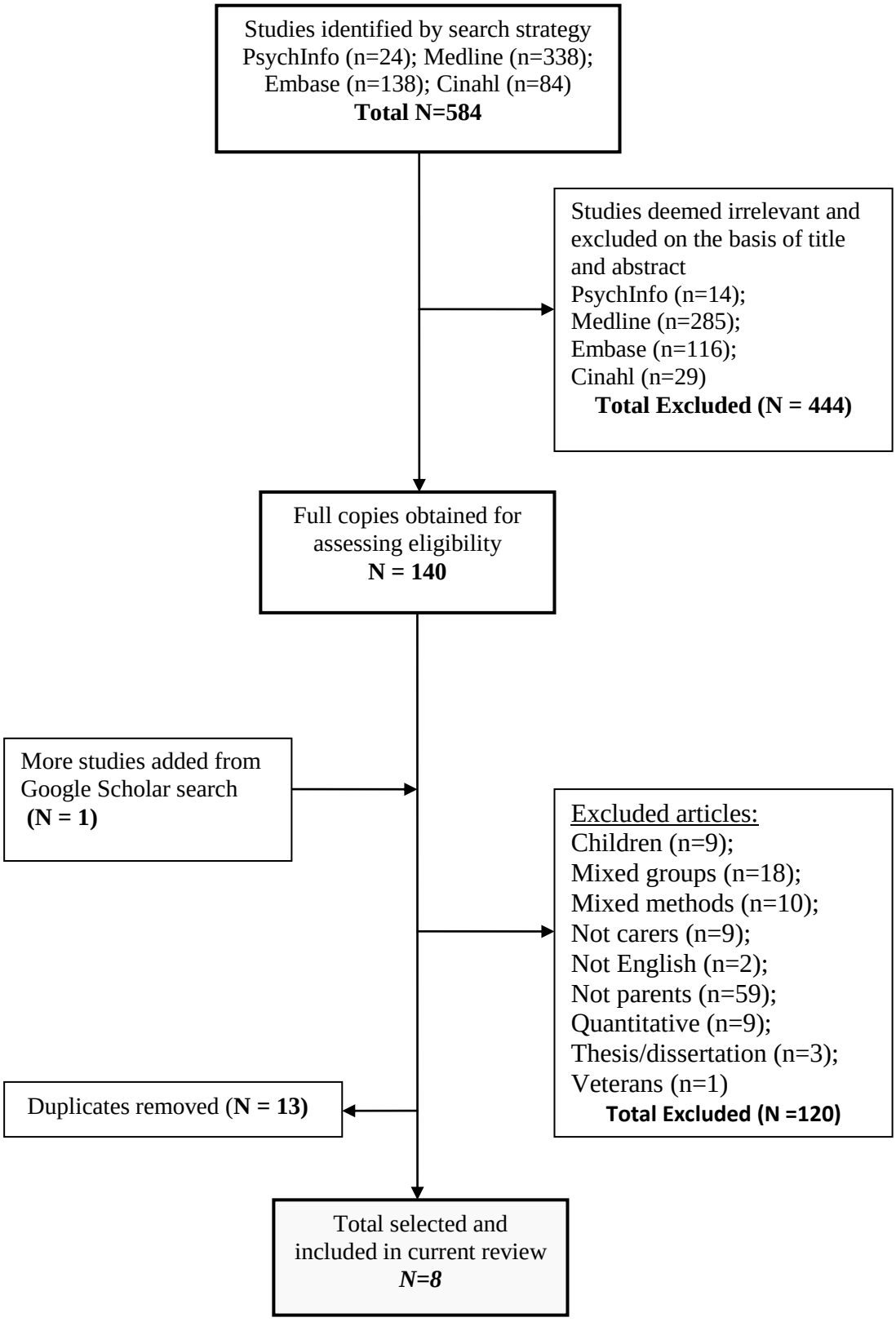

Figure 1. Flow Chart of Search Strategy

Method

Inclusion Criteria

Studies were considered appropriate for inclusion in the review if the primary focus or a substantial part of the study focused on exploring the experience of parent caregivers of adult children who had sustained an ABI. Studies needed to:

1. Have used a qualitative design.
2. Be published in peer reviewed journals.
3. Report primary data.
4. Be published in English.
5. In order to access as much research as possible, papers that have sampled parents and other carer types will only be included if the parents make up at least 50% of the sample, *and* it is possible to extract findings and quotations relating specifically to the experiences of parental carers.
6. The adult children had to have been treated in hospital for an ABI.

Exclusion criteria

1. Where the adult child had not sustained an ABI
2. Use of quantitative or mixed methods.
3. Research on military personnel.

Critical appraisal

The appraisal of quality in qualitative research is a subject of ongoing discussion. This is partly due to the unease felt by researchers that qualitative data should be judged against appropriate criteria, rather than what is appropriate to quantitative research (Smith, Flowers & Larkin, 2009). Even amongst qualitative

researchers, there is debate as to what criteria should be used. Dixon-Woods, Booth and Sutton (2007) found that there was little consistency in their analysis of 42 systematic reviews of qualitative studies. A wide range of appraisal techniques had been employed including, for example, checklists and criteria relating to study characteristics. In some articles, there was no mention of the quality assessment employed (Dixon-Woods et al., 2007).

Some researchers, for example Willig (2001), maintained that data collected and analysed in a particular method must be judged qualitatively from an appropriate perspective. Madill, Jordan and Shirley (2000) suggested that "Qualitative researchers have a responsibility to make their epistemological position clear, conduct their research in a manner consistent with that position, and present their findings in a way that allows them to be evaluated appropriately" (Madill, Jordan and Shirley, 2000. p. 17). However, Yardley (2000) encouraged embracing methods of assessing quality that are open-ended and flexible, and applicable to many methods. For Yardley, the characteristics of good qualitative research must include: sensitivity to context; commitment, rigour, transparency and coherence, impact and importance. Smith et al. (2009) endorsed these criteria because they are broad ranging and applicable to many types of qualitative work. Smith (2011) drew further on Yardley's work in his paper about the development of assessing quality in IPA research. Interestingly, a study by Dixon-Woods, Sutton et al. (2007) looked at comparing three methods of assessing quality in qualitative research and found that agreement in categorizing papers across the three methods was slight. However, it seemed that using a structured assessment tool encouraged reviewers to be more explicit about their thoughts. Therefore it was decided to use an appraisal checklist adapted from established appraisal tools (Critical Appraisal Skills Programme, 2006; Mays & Pope, 2000). Included studies were appraised in relation to the following ten questions:

1. Are the aims and objectives clear (e.g. clear statement of aims, relevance of study)?
2. Is the research setting or context clearly described?
3. Is the qualitative design used appropriate to the research question (e.g. is justification given)?
4. Are the recruitment strategy and participant characteristics described clearly?
5. Is there a clear description of the data collection and is it appropriate to the research question?
6. Is the data analysis rigorous and grounded in the data?
7. Has the researcher reflected on his/her own influence throughout the research process?
8. Have ethical issues been taken into consideration?
9. Is there a clear statement of findings (e.g. in relation to original research question? Are strengths and weaknesses addressed)?
10. Does the study contribute to existing knowledge?

Each study was scored on how well it met the above criteria and given an outcome rating according to guidelines suggested by Cesario, Morin and Santa-Donato (2001) and the Scottish Intercollegiate Guidelines Network (SIGN, 2008). Three points were awarded against each criterion if well addressed; 2 points were awarded if adequately addressed; 1 point awarded if poorly addressed and 0 points were awarded if not reported or appropriate. A study scoring maximum points would have a score of 30. If studies scored between 22.5-30 they would be given '++'; this would mean that 75%-100% of the criteria had been met and that the risk of bias was low. Studies scoring between 15-22.5 were rated as '+' and that 50%-75% of the criteria had been met with a moderate risk of bias. Studies awarded a score of 15 or less were given a '-'which indicated a high risk of bias.

Each paper was rated independently by two reviewers. A third reviewer rated 4 of the papers in order to achieve greater reliability of the ratings. Agreement was reached on 86% of included studies (68/80 criteria). Final agreement was reached after discussion with the three reviewers.

Results

Data extraction and synthesis

The three studies by Wongvatunyu and Porter were included in the review as although the data was collected initially in the 2005 study, the authors reported on different aspects of the experience of caring. The important characteristics of the included studies (e.g. setting, method of data collection, clinical implications) were extracted and are presented in Table 1 below:

Table 1. Data extracted from the included studies.

Study author(s)	Carson, (1993). USA	Kao & Stuifbergen, (2004) USA	Wongvatunyu & porter, (2005) USA	Wongvatunyu & Porter, (2008 a) USA	Wongvatunyu & porter, (2008b) USA	Fumiyo, Sumie, Akiko & Yasuko, (2009). Japan	Engstrom & Soderberg, (2011) Sweden	Jones & Morris, (2012) UK
Aims of study	To discover social and psychological processes experienced by parents of adult children post TBI, and how they perceive factors influencing the processes.	To describe the meaning of the experience of relationships between adult children with TBI and mothers	To describe mothers' experience of helping young adults with TBI.	To describe the changes that mothers perceived in family life post TBI	To explore the personal -social context of the experience of mothers who care for adult children post TBI	To elucidate the adjustment process of mothers caring for sons with TBI over 5 years to aid social rehabilitation of mothers an sons	To describe transitions experienced by close relatives of persons with TBI	To explore experiences of adult stroke survivors and their parent carers.
Time since injury and injury severity if applicable	8-70 months. Moderate to severe TBI	2-11 years PTA 7-102 days	8 months -20 years Moderate to severe TBI	8 months -20 years Moderate to severe TBI	8 months -20 years Moderate to severe TBI	5 years ?severity	10-26 years ?severity	1yr 7mth – 7yr 6mths. Stroke
Participants and setting	Parents from 20 families, numbers and gender unclear). USA. Recruited	12 mothers. Recruited through Brain injury Association of Colorado.	7 mothers recruited by convenience methods. Missouri, USA.	7 mothers. USA. Convenience methods	7 mothers. USA. Convenience methods	13 mothers. Japan. Interviewed in hospital meeting rooms. Referred by hospitals or	5 women, Sweden. Includes 3 mothers. Recruited through a brain injury association.	6 mothers, 5 fathers, 6 stroke survivors. Recruited from "Different Strokes" using web and paper adverts. Interviewed in own homes.

	through National head Injury Foundation. Interviewed in own homes					brain injury organisations.	interviews in their own homes	UK
Method of data collection	Semi-structured interviews. Grounded theory. 2nd interview with 3 families.	Phenomenology. semi-structured interviews with set questions.	A descriptive phenomenological method. Semi-structured interviews, open-ended questions. 3 interviews with each participant over 2-month period.	Phenomenological. Semi structured interviews. 3 interviews with each participant over 2 month period	Phenomenological. Semi structured interviews. 3 interviews with each participant over 2 month period	A qualitative, descriptive, inductive research study. Semi-structured interviews analysed using a modified grounded theory approach.	Interpretative, descriptive. Semi-structured interviews.	IPA, semi-structured interviews. Each group's data analysed separately then synthesised.
Summary of main findings	A 3-phase theory. Parents went from centering on childrens' needs to fostering independence to seeking stability. Not necessarily a linear progression. Dramatic	Mothers struggled with uncertainty, how to balance protection v. autonomy. Pressured relationships with children and spouses. Defense mechanisms to protect against unacceptable realities	Mothers stimulated children's brains from outset and maintained rehabilitation after discharge Protecting their child, trying to make their lives as normal as possible, using the home as a rehabilitation centre. Each	Family life permanently changed. Family members struggled in different ways to the injured adult and to the mother. Financial problems were significant for some families. Some families split in order to meet needs of injured person.	Mothers unprepared for role. Unanswered questions. Coping with role changes. Centrality of child's needs. Lack of support from professionals. Lack of knowledge. Mothers focus on what their children can do and motivate them to carry on. Can	5 stages in adjustment process; avoidance (avoiding contact with son because it's too painful), closed support, support seeking, withdrawal and	4 categories of transitions: starting point; pattern of daily living; relationships and social life. On call continually. Importance of hope. Appreciating small things. Disrupting effect of	Parents adjusted well to caring but adult children did not adjust well to being cared for. Both adult children and carers experienced emotional turmoil. Difficult to balance protection/promoting independence. Caring role affected relationships with other family

	effect on families. The parents know their children better than anyone else.		mother had to deal with their own particular problem significant to her. Advocacy to help their child fulfil their potential. Trying to meet needs of other family members.		recognise that they do have skills to do the job.	reconstruction . Not linear but cyclical.	chronic illness	members. They experienced narrowing of social horizons. Positive elements to caring present. Confirms stroke as a "family dilemma"
Clinical implications .	Clinicians need to use parents as a source of information about patients. The study allows nurses to understand more of the experience of parents and support them better as they felt isolated and abandoned.	Need for enhanced and extended individualised care for families as long as needed. Need for a more systematic and integrated discharge process.	Enhanced understanding of how mothers continue with rehabilitation when professional services stop. Importance of professionals ability to foster confidence and value carers' input. Need for continued support.	Clinicians (nurses in this instance) need to consider the disruptive effect of TBI on families from perspective of mothers. This study enables nurses to engage in therapeutic conversations with mothers regarding change in the family functioning.	Inform clinicians' interactions with mothers and also understand the kind of problems they have to deal with such as accessing services. Use the mothers' knowledge about their children when developing discharge and rehabilitation programmes.	Extending knowledge about the experience of this population in a country where there is little organised rehabilitation provided, so families are generally unsupported.	Carers need support in order to provide support, for as long as needed. Avoid social isolation for themselves and the injured person.	Clinicians should carefully consider the significant change in parent-adult child relationship after a stroke. A need to tailor post stroke interventions for younger patients. Disruption of family life cycle an important factor to consider when developing interventions.

Table 2 Appraisal scores of included studies.

Studies.	1	2	3	4	5	6	7	8	9	10	Total score /30	Overall rating
Carson, 1993	3	2	2	2	2	3	0	1	2	2	19/30	+
Kao & Stuifbergen 2004	3	3	2	3	3	3	3	1	2	2	25/30	++
Wongvatunyu & Porter, 2005	3	3	3	3	2	2	0	1	3	2	22/30	+
Wongvatunyu & Porter, 2008a	3	3	3	3	2	2	0	1	3	3	23/30	++
Wongvatunyu & Porter, 2008b	3	3	3	3	2	2	0	1	3	2	22/30	+
Fumiyo, Sumie, Akiko & Yasuko, 2009	3	2	3	3	2	3	0	0	3	2	21/30	+
Engstrom & soderberg, 2011	3	2	2	3	2	2	0	2	3	2	23/30	++
Jones & Morris, 2013	3	3	3	3	3	3	2	1	3	3	26/30	++

Quality criteria

1. Are the aims and objectives clear?
2. Is the research setting or context clearly described?
3. Is the qualitative design appropriate to the research question?
4. Is the recruitment strategy and participant characteristics described clearly?
5. Is there a clear and systematic description of the data collection?
6. Is the data analysis rigorous and grounded in the data?
7. Has the researcher reflected on his/her own influence throughout the research process?
8. Have ethical issues been taken into consideration?
9. Is there a clear statement of findings?
10. Does the study contribute anything of value to existing knowledge?

3: Well addressed. 2: Adequately addressed. 1: Poorly addressed. 0: Not reported/applicable.

Characteristics of included studies

Four of the included studies were of good methodological quality, scoring an overall rating of '++' (Kao & Stuifbergen, 2004; Wongvatunyu & Porter, 2008a; Engstrom & Soderberg, 2011; Jones & Morris, 2013). The remaining four studies scored an overall adequate rating '+' (Carson, 1993; Wongvatunyu & Porter, 2005; Wongvatunyu & Porter, 2008b; Fumiyo, Sumie, Akiko & Yasuko, 2009.). All the studies provided clear aims and objectives and the research contexts were described in sufficient detail. The use of a qualitative design was appropriate for all the study aims, although there was a difference in how that method was described across the studies.

There was a range of qualitative methodologies used. Two studies specified a particular method; Interpretative Phenomenological Analysis (IPA) was used by Jones and Morris (2013) and Grounded Theory by Carson (1993). Fumiyo et al. (2009) described their method as a 'modified grounded theory' approach. Engstrom and Soderberg (2011) used an 'interpretative, descriptive' approach. Wongvatunyu and Porter (2005, 2008a & 2008b) used a 'descriptive phenomenological' approach in their collection and analysis of data. Kao and Stuifbergen (2004) used a 'phenomenological' approach. Although the studies described their analytical methods in different ways, it was not apparent to the reviewer that the types of analysis were substantively different. All used an interpretive, phenomenological stance. Fumiyo et al. (2009) used a "modified grounded theory" approach and it was not clear how that differed from the "grounded theory" approach taken by Carson (1993). Data collection involved using semi-structured or open-ended interviews with individuals, either single interviews or at two time points (Carson, 1993) or at three time points (Wongvatunyu & Porter, 2005). Only one study (Kao & Stuifbergen,

2004) provided details of the interview schedule. Wongvatunyu and Porter (2005; 2008a; 2008b) gave examples of the questions they asked. More detail on the questions asked would have made the data collection more transparent.

Participant groups included 55 mothers, five fathers and a further number of carers from 20 families where it is not clear how many were involved. The majority of participants were interviewed in their own homes, with the remainder interviewed at a hospital or clinic setting. Participants were recruited voluntarily through brain injury associations, stroke associations or advertisements in clinics, apart from the participants in the Fumiyo et al. (2009) study, who had been referred by hospitals or brain injury associations. The time between injury and the interviews varied across papers, from eight months to 20 years. The participants' adult children's injury severity ranged from 'moderate' to 'severe' where stated.

All the included studies paid attention to the voices of the participants and analysis was grounded in the data. There were clear links between data and implications drawn by the researchers with appropriate extracts from transcripts. Only two studies (Kao & Stuifbergen, 2004; Jones & Morris, 2013) commented on the impact of the researchers on their studies. Kao was a TBI survivor and wrote on the possible effects that may have had on the participants' responses. Jones and Morris took measures to reduce researcher bias by following closely the steps outlined by Smith, Flowers & Larkin (2009). Jones also kept a reflective account to enhance transparency in the research process and discussed findings with a colleague. There was little detail given in the majority of studies relating to the ethical considerations

such as ethical approval or the possible impact on the participants of taking part in the research.

Meta-synthesis

Meta-synthesis involves the examination, comparison and interpretation of the findings of published qualitative studies in order to extend the knowledge base on a particular area of interest. Papers are identified and rated methodologically. Data is extracted and then findings are summarised and synthesised (Salter et al., 2008). In this systematic review the phenomenon in question was the experience of parents caring for adult children post ABI.

The systematic review question was "How do parents experience care-giving for their adult children after Acquired Brain Injury?". A meta-synthesis of the eight studies included in the current review were organised into four broad, inter-related themes:

1. Emotional turmoil of parents
2. Centrality of caring for their adult child
3. Protection/promoting independence
4. The effects on family relationships

Emotional turmoil of parents

The qualitative research methods used allowed the reader to hear the voices of the participants in all of the papers. Although the participants lived in different countries (UK, Japan and USA) and time since injury had varied significantly, their lives had changed abruptly for the worse (Engstrom & Soderberg, 2011). A transition

had taken place for them and their children in which they found themselves caring for an adult child who had been autonomous, in a world that seemed predictable (Engstrom & Soderberg, 2011). The uncertainty of their child's prognosis was agonising (Kao & Stuifbergen, 2004). The emotional turmoil was ongoing and could resurface at critical time points. One father talked of the mourning experienced as he grieved for aspects of the child he had lost, and that these grief experiences could occur even many years after the stroke (Jones & Morris, 2013). Often the emotional pain did not pass (Wongvatunyu & Porter, 2008a). Participants experienced conflicting feelings of love, worry, hatred and guilt (Kao & Stuifbergen, 2004).

Parents tried to defend themselves against unacceptable realities in a number of ways. Several studies reported that hope was of paramount importance (Kao & Stuifbergen, 2004; Wongvatunyu & Porter, 2008a; Engstrom & Soderberg, 2011) and enabled parents to keep going. Some parents found that making themselves choose an optimistic stance and be strong in order to support other family members was a positive coping strategy (Kao & Stuifbergen, 2004). One study reported parents making downward comparisons with others in their situation, which allowed them to see their own circumstances in a more manageable light (Carson, 1993). Parents who saw themselves as able to help their children and saw their children as able to learn and progress, experienced less burden and stress (Wongvatunyu & Porter, 2008a). At times however, parents perceived that they were not given the recognition they deserved as experts on their own children, and Wongvatunyu and Porter (2008a) suggested that professionals could gain knowledge from parents about their patients. This would also improve the relationship between staff and family care givers.

Centrality of caring for their adult child

Each study included in the current review showed that the parents started to care-give from the very beginning of their new, unwanted life as parents of adult survivors. Trying to make sense of what had happened involved parents trying to find out as much as possible about the prognosis for their child and how they could become involved (Engstrom & Soderberg, 2011; Wongvatunyu & Porter, 2005). Goal setting was important; perhaps for the parents as much as those being cared for, as a way of trying to regain a sense of control over the chaos the ABIs had caused. Apart from the participants in the Fumiyo et al. study (2009), the parents immediately sought proximity to their children and wanted to be with them as much as possible. This appeared to be a return to a former, more intensive form of parenting. Parents wanted to be involved in care and rehabilitation from the beginning. For some, it was seen as a continuation of the parenting role (Wongvatunyu & Porter, 2008a; Jones & Morris, 2012); for others new parenting skills had to be learned (Carson, 1993). Other parents drew on past employment experience to help them carry out responsibilities (Wongvatunyu & Porter, 2008a; Jones & Morris, 2012). Parents put everything else aside to concentrate on their injured child and lived with a 'self-imposed embargo' on everything that could get in the way (Carson, 1993).

Rehabilitation was seen as their responsibility as parents (both by themselves and the professionals) and not to be left solely to the professionals. Often parents described being unprepared and untrained for the job, though they instinctively adjusted their strategies to stimulate and retrain their children (Fumiyo et al., 2009; Wongvatunyu & Porter, 2005). This involved playing familiar music, reading aloud to their children, and encouraging exercise 'to get a good blood supply to the brain'

(Wongvatunyu & Porter, 2005). Several studies described parents being 'on stand-by' constantly (Engstrom & Soderberg, 2011; Kao & Stuifbergen, 2004). They had to rearrange their time and employment in order to see to their children's needs. The family home became the rehabilitation base as it was perceived to be safe and familiar. Their social circles diminished as they continued to be constantly available for their children at the expense of their own needs. The parents in Kao and Stuifbergen's study (2004) found that rehabilitation became their purpose and advocating for their child was "a mission". However, many participants reported a lack of preparation and training to help them maintain the progress their children had made (Engstrom & Soderberg, 2011). Services had to be sought out and it was important to parents that their children had access to whatever they needed in order to progress (Wongvatunyu & Porter, 2005).

Protection vs. independence

This third theme is closely related to the previous theme in that part of the rehabilitation process that parents undertook involved promoting independence in their adult children. Although all the parents referred to their sons and daughters as children ('my child'), they knew intellectually that they were adult children who had enjoyed various degrees of autonomy and distance from the family home prior to their accidents (Wongvatunyu & Porter, 2005; Jones & Morris, 2012). Part of the pain that parents experienced was caused by seeing their children having to come to terms with loss of independence and freedom. However, encouraging independence and self-reliance would involve taking risks for these parents. Parents spoke of needing to allow their children to make their own mistakes. This was a daunting prospect for parents. The study by Carson (1993) noted that keeping their child safe and

preventing re-injury was exhausting, as parents constantly monitored their children's progress, health, and environment. Other parents planned ahead to make sure that accidents did not happen, installed night lights in their houses, had readily available lists of contact numbers (Wongvatunyu & Porter, 2005).

Maintaining a balance between holding close and letting go was necessary but difficult (Kao & Stuifbergen, 2004) because parents experienced a strong urge to over-protect (Jones & Morris, 2012). One father, however, voiced frustration that his son lacked motivation and appeared to be happy to allow others to look after him (Jones & Morris, 2012). It was an 'enormous sorrow' for parents to watch as their children experienced a narrowing of horizons imposed by a lack of understanding about brain injury and a lack of access to meaningful opportunities (Kao & Stuifbergen, 2004). The study by Fumiyo et al. (2009) offered a 5-stage framework by which to conceptualise the process of adjustment of mothers of sons after TBI. Although the authors acknowledged that there would be differences in how mothers proceed through the stages, there was an implicit understanding that mothers *would* move through the different stages. One of the stages was called "Withdrawal" and this involved mothers pulling back from their sons in order to foster their independence, but also to foster their own re-emergence into the outside world. This does not resonate with the findings in the other studies which did not report a withdrawal but instead suggested that the experience of caring was continuous. Perhaps these differences could be explained by the time of interview in the parents' journeys as carers. The participants in the Fumiyo et al. (2009) study were interviewed up to five years post injury, so perhaps others would reach the "withdrawal" stage in time.

The effects on family relationships

The final theme describes how the way families related to each other was changed dramatically by brain injury. Jones and Morris (2012) commented that a stroke was confirmed as a "family dilemma". Most of the participants in the studies included in the current review were mothers, and they tended to assume the largest proportion of care giving. Surprisingly, not all of these relationship changes were experienced negatively. For many of the mothers in Fumiyo et al.'s (2009) study, the change was experienced as a welcome return to the exclusive relationship that they had enjoyed with their child when was an infant. Other participants enjoyed a return to a close relationship too, but it was not without tensions. Jones and Morris (2012) had also interviewed the adult children who sometimes struggled with their enforced return to dependence on their parents and resented their loss of autonomy and privacy.

The studies also revealed that parents questioned the identity of their children post ABI. Different behaviours and abilities displayed in their children made them search out the essence of the 'old child' in the make up of the 'new child' who now lived with them. Parents in Carson's (1993) study grappled with losing one child and getting another one in his or her place. This was echoed in some of the other studies (e.g. Wongvatunyu & Porter, 2008a).

Parents were very conscious of the fact that putting all their energies into caring for the injured child could be at the expense of attending to other family members (Engstrom & Soderberg, 2011; Wongvatunyu & Porter, 2008b). Siblings of the injured child sometimes resented the loss of attention they received (Wongvatunyu & Porter, 2008b). They appeared to be uncomfortable with, and embarrassed by, their

disabled sibling. Spouses felt ignored as their husbands or wives were too exhausted to invest time and energy into their relationships. Kao and Stuifbergen (2004) described this erosion of spousal connection as 'marital menace'. A loss of sexual intimacy was reported in other studies because couples experienced tensions due to dealing with their new family circumstances in different ways (Jones & Morris, 2012). Carson (1993) makes reference to the development of their re-identification as a couple as being halted, and in rare instances the family home was split up so that the mother could move closer to rehabilitation facilities (Wongvatunyu & Porter, 2008b).

Significantly, some studies reported positive aspects of care giving. There was gratitude that children had survived and families could be brought closer together (Jones & Morris, 2012; Wongvatunyu & Porter, 2008b). Some parents noticed that they and their family members had different priorities post accident and they were able to appreciate aspects of living that may have gone unnoticed before (Engstrom & Soderberg, 2011).

Limitations of existing literature

The literature search indicated a lack of qualitative research examining the experience of parent caregivers of adults with ABI. Four papers focused solely on the experience of parent caregivers, whilst the others included other family caregivers and/or survivors. Given that so many survivors of ABI are younger adults who are cared for by parents, this represents a gap in the literature.

The included studies were overall of an adequate to good standard of methodological quality, but there was lack of detail about the reasons for choosing

particular methodological approaches, and a wide variety in the level of description or interpretation. In some papers there were lengthy descriptions of the analysis process but these could be complicated, and it was not always clear how studies differed in terms of the output.

Only the Kao and Stuifbergen (2004) and the Jones and Morris (2012) studies commented on the possible effects they as researchers had on the research process. The study by Kao and Stuifbergen (2004) was interesting as one of the researchers was herself a TBI survivor. There was a lack of reflection on the impact of researcher knowledge, culture, possible power imbalances or preconceptions reported in the other papers. Information on the ethical aspects of the studies was poorly reported across the studies, apart from the Engstrom and Soderberg (2011) study. There was also little detail provided regarding the interview schedules. However, in spite of some significant aspects of the research process not being reported, the results did provide some interesting insights into the lived experience of those who care for adult children with ABI.

Discussion

The purpose of this study was to examine the qualitative literature relating to how parents experience caring for their adult child with ABI. The use of qualitative methods allowed for the reporting of both the convergent and divergent experiences of the participants who took part in the included studies. Parents assumed the role of caregivers naturally, without question. They committed themselves whole-heartedly from the beginning to care for and encourage their children to make as good a recovery as possible. Hope played an important part in enabling parents to stay committed to the task although they faced many problems along the way. Many participants spoke of their child's injuries as a traumatic event, and parents continued to experience distress over a long period of time. Once their children's conditions had stabilised, parents began to realise that their commitment to the care giving role would be life-long, particularly for those who had experienced more severe injuries. Being on standby and monitoring their children's safety, health and rehabilitation became part of every day living. Mothers in particular adjusted their employment and social lives to centre on their injured children often at the expense of their own social lives, freedom, relationships with other family members and their marital relationships. The ABI was something that happened to the whole family, and not just to the individual with the ABI. There were also positive aspects to the caring role such as closeness with family members and an appreciation of aspects of living that may have gone unnoticed before.

The included studies explored the experience of caring for adult children with an ABI in a variety of research contexts. The age of both carers and adults with ABI

varied, as did the circumstances and severity of injury. There was a wide range of time since injury both within and between studies. There was also difference in the support and service provision for both survivors and their parent caregivers. However, the overall quality of the studies was either good or adequate. The risk of bias was reduced to a good or adequate level. The findings of the included studies are therefore likely to be trustworthy because of the overall level of methodological rigour. It should be noted that although the current reviewer appraised included studies in relation to the research question, the appraisal tool used perhaps was more suited to the appraisal of the quality of the writing of a research paper rather than the quality of the methodology of the study. Quality criteria 2 and 4 cover clarity of description of the research setting, recruitment strategy and patient characteristics. For example, the study by Jones and Morris (2013) was rated as "good" overall and had satisfied the above criteria. However, regarding the review question i.e. the experience of parent carers, this study included the experience of both parents and adult children, so recruitment did not focus solely on the population specified by the review question. Similarly, the study by Engstrom and Soderberg (2011) was rated as "good", although the participants were close relatives of the injured persons rather than parent caregivers exclusively.

Theoretical relevance and clinical implications

The synthesis of the studies suggests that parents do not experience the role changes that spouses may have to contend with after ABI (Buschenfeld & Morris, 2009). However, in the role as mother or parent they have to contend with circumstances that are outwith the usual experience of parenting. Wongvatunyu and Porter (2008a) cited research that stated that under normal circumstances mothers will

prioritise caring for her child if that child is vulnerable or under threat. Clark, Stedmon and Margison (2008) suggested that parents' urges to protect and seek proximity with their children could be understood from the perspective of attachment theory. Crittenden (2006) stated that protecting children was a basic drive. As Clark et al. (2008) suggested, the occurrence of a TBI could activate the protective response to avoid separation from their children. Although Clark et al. (2008) focused on the experience of mothers of younger children, it appears that the findings of this review that the urge to protect is unaffected by the age of the "child." This could help to explain why parents sought proximity so soon after the injuries occurred. Clark et al. (2008) suggested that at a clinical level, an understanding of the need for proximity would be useful in planning rehabilitation interventions with families.

The findings from the current review have potential practice implications for professionals working with this population. Such qualitative research can enhance professionals' understanding of what some of the aspects of the experience of care giving are. Qualitative methods have produced a more comprehensive picture of the reality of living with stroke than quantitative methods alone could have done (Salter, Hellings, Foley & Teasell, 2008) and it is hoped that this current review has enhanced the understanding of the experience of parent care givers in ABI. Although the parents did not perhaps experience a change of role, the occurrence of an ABI had put unanticipated demands on them. The data suggests that parents need support and information from the beginning, and that their support needs may persist for a considerable time It also must be available to them for as long as it is needed (Kerr & Smith, 2001). Kao and Stuifbergen (2004) highlighted the need for a more systematic

and integrated discharge process and this has been found in other research (Rocha Pereira & Rebelo Botelho, 2011).

Some parents felt that their expertise was neither invited nor appreciated. It is important that professionals acknowledge that parents are a vital resource in that they know their children better than anyone else, and that they will be expected to carry on with rehabilitation post discharge. Rehabilitation goals that are negotiated collaboratively with survivors and parents are more likely to be successful (Prigitano, 2000). Parents were committed to maintaining rehabilitation gains made during the inpatient phase but they need education and training.

Many parents felt isolated in their care-giving role and this is an important issue to be addressed. Carson (1993) pointed out that this was important information for nurses to be aware of when dealing with this population. Wongvatunyu and Porter (2008b) highlighted that such information would inform therapeutic conversations with parents and allow parents to discuss the issues that were significant to them. This has been confirmed in other research, which highlighted that if care givers perceived that they were listened to and understood, then communication between parents and professionals would be more positive for all concerned (Hunt & Smith, 2004). There was a tendency for parents to put their own needs and emotions to one side in order to try to meet the needs of their injured child, which is replicated in other care giver research (Buschenfeld & Morris, 2009). Professionals could use this information to enable parents to discuss difficult emotions such as anger or guilt by normalising these emotions in the caregiver population.

The review also highlighted the need for parents to have access to instrumental support. This could begin before discharge home and take the form of information on how to access respite care, professional services, advice on statutory benefits, professional carers.

The results have shown that parents can experience relationship difficulties such as those highlighted by Jones and Morris (2012) and Kao and Stuifbergen (2004). Professionals need to know about the stresses caring for an adult child can bring into a family unit and incorporate ways of coping with these issues in rehabilitation for the family and not just the individual. A Clinical Psychologist or Neuropsychologist could contribute to rehabilitation professionals' training by outlining psychological theory such as attachment or stress and coping models and their relevance to the experience of care givers. An example would be raising the awareness of parental proximity seeking at the acute stage of the patients' treatment. An understanding of parents' behaviour may lead to more sympathetic staff attributions about their need to be on the ward at all times.

Future research

The review has highlighted that the experience of parental caregivers is an underdeveloped area of research. Reviews in the past have either concentrated on the experience of mixed carer groups or comparisons between two carer groups. More research is needed that focuses on the experience of particular groups such as parents or spouses or children. The majority of parents in this review were mothers and it would be very useful to explore further the experience of fathers as care givers. More

research on the impact of care giving on intimate relationships of parents would be helpful as the existing research focuses more on the spousal experience.

The included papers covered a wide time span in time since injury. The nature and severity of the injuries were varied. Although interesting results were obtained, there is a need for further research that examines the experience of particular populations at significant points along the care giving journey, thus studying the experiences of more homogeneous participant groups.

Conclusion

The findings of this systematic review resulted in four inter-related themes: Emotional turmoil of parents; Centrality of caring for the adult child; Protection/promoting independence and finally, the Effects on family relationships. These themes explored the multifaceted experience of caring for adult children post ABI. The included papers indicated that as time passed, difficulties did not necessarily decrease but changed in nature. Services were often scarce or non-existent with the result that parents experienced isolation. This was compounded by feelings of marginalisation as their expertise as those who know their children best was neither acknowledged nor sought. The determination to carry on with rehabilitation post discharge was often at the cost of their social life, employment and health. Parents experienced a tension between protecting their children from further harm and recognizing that they had to encourage them to be as independent as possible. Family relationships were put under strain as a result of the new reality they had to face. In order to help themselves cope with their new reality parents used strategies such as maintaining hope and a positive stance, downward comparisons and seeing their children as capable of making progress.

Clinical implications and ideas for future research have been discussed in relation to this significant caregiver population.

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PART II

EMPIRICAL STUDY

Title: Caring for an Adult Child after Traumatic Brain Injury: The First Four to Six Weeks at Home

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(This journal article is written according to author guidelines for the journal *Neuropsychological Rehabilitation*, Appendix C)

Abstract

A qualitative research methodology was used to explore the experience of parents who care for their adult children who have sustained a severe traumatic brain injury (TBI), during the first four to six weeks at home. Semi-structured interviews were carried out with six participants (5 mothers and 1 father). Interviews were transcribed verbatim and analysed using Interpretative Phenomenological Analysis (IPA). Four superordinate themes were identified which captured the experiences of participants: (1) "We're parents, not carers": carrying on with the parenting role; (2) "Being a parent is not enough": Barriers to care giving; (3) "We knew we could do it": factors that engender mastery; and (4) "Life is on hold"; the psychological, physical and social impact on parents. The results suggest that these parents faced many challenges that are not necessarily made easier because they are continuing in the parent role. The first few weeks at home is a time when they can feel unprepared and untrained to face these challenges but positive aspects to caregiving were also identified. Clinical implications and ideas for future research are discussed.

Key words: parents; traumatic brain injury; experiences; qualitative; caregiving.

Introduction

Caring for someone who has sustained a traumatic brain injury (TBI) can be very challenging. Previous research has identified that it is usually family members who assume the role of primary caregivers of people who have sustained a TBI once they have left hospital (Anderson, Simpson, Morey, Mok, Gosling & Gillett, 2009). Very often they have no training or expertise to cope with this sudden new world they have found themselves in (Brereton & Nolan, 2002). They have to learn by trial and error. Their needs are rarely assessed to see whether they are able or not to carry on with the rehabilitation and care needs that many traumatic brain injured patients require when they leave hospital (Brereton & Nolan, 2002). This situation is at odds with the Scottish Intercollegiate Guidelines Network (SIGN) guidelines (2013) where it was recommended that "Family and carers should be provided with access to ongoing support when the patient with brain injury is living within the community" (p 40). The breadth of caring duties they may have to deliver includes help with daily living tasks, personal care, rehabilitation activities, and cognitive therapy (Degeneffe, 2001).

Given that caregivers have to meet such a range of needs for their injured family member, it is unsurprising that many experience anxiety, depression, ill health, financial problems, role changes and social isolation (Knight, Devereaux & Godfrey, 1998; Oddy & Herbert, 2003; Minnes, Graffi, Nolte, Carlson & Harrick, 2000). A systematic review of depression and anxiety in parent and spousal carer groups (Ennis, Rosenbloom, Canzian & Topolovec-Vranic, 2013) highlighted the fact that many of those who sustain a TBI are young adults who will have a normal life expectancy and may have long term support needs. Ennis et al. (2013) pointed out that

it is usually parents or spouses who assume the carer role once the family member has been discharged from hospital and that these caregivers can experience significant levels of subjective burden which does not necessarily improve over time.

Caregivers can experience a range of unmet service and support needs, such as lack of respite services, information, and emotional or psychological support (Turner, Fleming, Ownsworth & Cornwell, 2011). Caregivers' needs change over time, depending on where they are on the rehabilitation continuum (Turner et al., 2011). It has been noted that in hospital, caregivers need information and emotional support, and once their family member has been discharged, they need support with behavioural issues and life planning (Turner et al., 2011; Rotondi, Sinkule, Balzer, Harris & Moldovan, 2007). Considering that informal caregivers save the UK exchequer approximately £87 billion a year (Jones & Morris, 2012) it would seem appropriate that investment is made in maintaining such a valuable resource. As Serio, Kreutzer and Gervasio (1995) have indicated, the success of rehabilitation in the TBI population is closely associated with the physical health, and degree of psychological burden, experienced by the caregivers.

The previous systematic review highlighted that the majority of young adults who sustain a TBI are cared for by their parents on discharge from hospital and yet there is little research to date that has focused on the experience of parents in particular. The systematic review also showed that parents may automatically assume the role of caregiver but they have had little in the way of preparation for that role. A better understanding of the meaning caregivers make of their experiences should lead to more effective services for this potentially vulnerable population. There is insufficient

research on the perceived levels of caregiver burden during the transition from hospital to home (Turner, Fleming, Parry, Vromans, Cornwell, Gordon et al., 2010) Exploring the early period of care for adult children could inform practice in how best to support caregivers in the important period of transition from hospital-to-home.

Effective support, informed by applied research on the early stage post discharge may reduce the stress, burden and physical illness levels often experienced by caregivers further down the line. This would not only reduce the problems faced by caregivers and enhance the maintenance of rehabilitation gains made in hospital by the injured individuals, but also reduce demands on health services made by both injured people and their caregivers when resources are in short supply.

Method

Design

This was a qualitative study. The aim was to gain a clearer understanding of the beliefs and perceptions of parents who provide care for their adult son or daughter, with a severe traumatic brain injury, on their discharge from hospital and the first four to six weeks at home. Interpretative Phenomenological Analysis (IPA; Smith, 1996) was chosen as the most appropriate methodology as it aims to explore participants' lived experiences in their own words (Smith, Flowers & Larkin, 2009). IPA acknowledges the impact of the researcher in the research process and how he or she interprets the participants' interpretations of their experiences: the "double hermeneutic" (Smith et al., 2009; Smith, 2011). IPA is becomingly increasingly popular in many research areas, but is particularly suitable in health psychology (Brocki & Wearden, 2006; Smith et al., 2009).

Aims of the current study

This study aimed to explore the experiences of parents who are the main caregivers of adult children who have suffered a severe TBI, during the transition from hospital and the first four to six weeks at home. This is an under researched area in the rehabilitation journey of people with TBI and their family caregivers. Parent caregivers constitute a large part of the caregiver population yet relatively little is known about their perspectives. This study seeks to add to the currently small qualitative research knowledge base of the experience of parent caregivers of adult children. The results will inform clinicians' and policy makers' understandings of the experiences of caregivers during a very difficult and stressful time in their lives. It has been shown elsewhere that caregivers can experience stress and both physical and health problems from the early stages of injury to several years later (Davis et al., 2009). If more is understood about the nature of these stresses, and how they are experienced, then potential problems could be avoided or supported more appropriately. This could prevent unnecessary distress both at the time of discharge from hospital and in the months ahead. Professionals could benefit in that not only would their understanding be enriched, but they would be better able to engage in more therapeutic conversations with parents from the very early stages, thus improving communication and a working relationship with them. The hope is also to encourage service providers to audit their existing services and develop more user-friendly interventions. Listening to what service users need and want is in-keeping with the recommendations made by the guidelines published by SIGN (2013) guidelines and the Patient Focus and Public Involvement Initiatives (Scottish Executive, 2006). Therefore the current research question is 'How do parents

experience caring for their adult children with severe TBI during the first four to six weeks at home?'

Participants

Inclusion Criteria

In order to be eligible to take part in the study potential participants had to be:

1. The parent of an adult who had suffered a severe closed traumatic brain injury.
2. The main or co-caregiver of their son/daughter.
3. Fluent in English.
4. Be able to give informed consent to participate.

Exclusion Criteria

1. A child under the age of 17 at the time of injury or who had been treated in paediatric services.
2. People with a communication problem that would have made it difficult for them to articulate their experiences.
3. Unable to give informed consent.
4. A son/daughter who had suffered an acquired brain injury or a developmental disorder other than TBI.
5. The parent of an adult with a TBI, but not the main caregiver (i.e. if their child lived with a partner or was in residential care).

Recruitment

Participants were recruited through two sources; NHS neuropsychological staff (n=3) and Headway (n=3), a UK charity that aims to support people post head injury. Potential participants were identified by the multi-disciplinary team shortly before their family member was due to be discharged, or at a follow-up appointment in outpatient departments. Headway personnel would be aware of potential participants who had made contact with their local group. Those interested in participating in the study were given a Patient Information Sheet (Appendix D) and consent form (Appendix E) allowing the researcher to contact them. This included information that they were under no obligation to take part in the study and could withdraw at any time. If they wished to take part an appointment was made at a time and place convenient for them. Participant demographics are given in Table 1. All names have been changed.

Table 1. Participant Demographics.

Name of participant	**Age range**	**Relationship to TBI survivor**	**Participants' employment status at time of accident**	**Marital status Married (m)**	**Time from discharge to interview (weeks)**	**Length of stay in hospital (weeks)**	**Name of son/daughter**
Beth	50-55	mother	employed	m	5	20	Donald
Hassan	50-55	father	employed	m	4	22	Ahmed
Meg	45-50	mother	employed	m	5	10	James
Flora	45-50	mother	employed	m	5	24	John
Kate	60-65	mother	employed	m	7	40	Roddy
Rona	50-55	mother	employed	m	5	14	Anna

Table 2. Adult/Child Demographics

Son/daughter	Age	Gender	Health status as described by participants	Employment status at time of accident	In a romantic relationship at accident
Donald (Beth)	17-20	M	Memory problems, fatigue, left-sided weakness	Student/part time tradesman	yes
Ahmed (Hassan)	17-20	M	Slow speech/thinking, fatigue, mobility problems	Student	yes
James (Meg)	17-20	M	Fatigue, memory, speech, walking difficulties	Student	no
Anna (Rona)	24-27	F	Memory/concentration/low mood	Post-grad student/part time job	no
John (Flora)	17-20	M	Memory/processing speed/irritability/awareness problems	Student	yes
Roddy (Kate)	24-27	M	Wheelchair dependent/24 hour care/no speech/vision impairment	Tradesman	no

All patients had suffered a severe traumatic brain injury as categorised by the medical professionals involved in their care. The injuries were all classed as "closed", i.e. there was no penetration of the skull. Injuries were sustained in road traffic accidents.

Sampling and Sample Size

Purposive sampling is recommended in IPA (Smith et al., 2009). This involves recruiting participants who can provide insight into a particular phenomenon, in this case, the experience of caring for an adult son or daughter with a severe TBI during the first four to six weeks after discharge from hospital. The idiographic stance of IPA favours small participant groups as the emphasis is on the intensive analysis of individual experiences (Reid, Flowers & Larkin, 2005; Smith, 2011). It has been suggested that a group of four to ten participants are appropriate for a taught doctorate course thesis (Smith et al., 2009) and that an IPA study "typically involves a highly intensive and detailed analysis of the accounts produced by a comparatively small number of participants" (Larkin, Watts & Clifton, 2006).

This proved to be a hard to reach population, but according to the guidelines given by Smith et al. (2009) it was decided that six participants would be sufficient, given that the group was homogeneous in terms of carer relationship, type of closed severe traumatic brain injury, all incurred through road traffic accidents, and with children who were young adults. All participants live in a remote and rural area and are served by the same health board. The issue of sample size and homogeneity will be more fully explored in Part 3 of the thesis portfolio.

Ethical Issues

The study was reviewed by the DClinPsychol University of Edinburgh ethics committee. The study also received approval from the North of Scotland Research Ethics Committee, and management approval was granted by NHS Highland, Grampian and Lothian. The British Psychological Society's (BPS) Code of Conduct, Ethical Principles and Guidelines (BPS, 2006) was consulted before the interviews took place and each step of the process was carried out with this in view (see Appendix F for ethical approval).

Confidentiality

Participants were made aware of confidentiality issues by provision of written and verbal information. All names of participants, family members and clinicians were changed. Any details such as type of injury or place of accident that could have been used to identify participants were omitted as far as possible. Participants signed a form giving permission for the researcher to record the interviews with a digital recorder, and once the interviews were transcribed, these were erased. All data was

stored on an NHS password protected computer in line with NHS data protection protocols. It was made clear to participants at the interviews that if there was any risk evident to themselves or others, appropriate staff would be informed.

Data Collection

Interview schedule

Each participant was interviewed using a semi-structured interview guide (Appendix G). Questions were open-ended, singular and neutral (Hunt & Smith, 2004; Patton, 1990; Willig, 2001). The interview schedule aimed to facilitate conversation about what was important to participants, not dictate the content. Prompts were used in order to further explore issues that were important to the participant (Smith & Eatough, 2007). Not all the questions were asked in every interview but issues that were significant to each individual participant were further explored. This flexibility allowed for unanticipated topics to arise.

Interview procedure

Participants were interviewed at a place of their choosing (five in their own homes, one in a hospital room). Each interview was digitally recorded. The interviews were recorded and transcribed verbatim by the researcher, one at a time, in line with IPA's idiographic approach. Interviews lasted between 45-90 minutes (mean 72 minutes).

Data Analysis

The principles outlined by Smith et al. (2009) were followed in analysing the data. The analysis steps were:

1. ***Reading and re-reading***

This stage of analysis involved reading and re-reading the transcripts. Reflections were noted at the bottom of each page to keep them separate from notes taken in step 2 such as "Beth's voice sounds very flat" or "I should have kept quiet at that point and let her have time to think." Words or phrases that appeared significant were underlined.

2. ***Initial noting***

The second step involved reading the first transcript and making a note of anything that was thought to be important, line-by-line. Comments were noted on the left hand side of the transcript. An attempt was made to differentiate between *descriptive* comments, *linguistic* comments and *conceptual* comments, which were more interpretative or questioning.

3. ***Developing emergent themes***

Emergent themes were written on the right hand side of the transcripts. Smith et al. (2008) suggest that themes are made up of phrases that shift the initial notes to a more abstract, conceptual level. A significant part of moving on from notes to emergent themes involves an attempt to "produce a concise and pithy statement of what was important in the various comments attached to a piece of transcript" (p.92). These

statements reflect both the participant's words and the researcher's interpretation (Appendix H).

4. ***Searching for connections across emergent themes***

Step 4 involved reading through the list of emergent themes and starting to look for connections across them, and organising them conceptually. A list of super ordinate themes was produced for the first transcript.

5. ***Moving to the next case***

This step involved moving to the next transcript and repeating the whole process. In keeping with IPA's idiographic stance the researcher tried to "bracket off" findings from the previous transcript and approach each transcript with an open mind and allow novel themes to emerge.

6. ***Looking for patterns across cases***

By this stage of the process a table of super ordinate themes from each participant had been produced. During this stage of analysis some themes were renamed or moved between groups of themes. Themes that were unique to particular individuals were either excluded or incorporated under a super-ordinate theme where appropriate (Smith, 2011). Appendix I contains a selection of supporting extracts from transcripts chosen to reflect themes. The resultant super-ordinate and sub-ordinate themes were tabulated to examine frequency (Appendix J).

Ensuring Quality

How best to demonstrate quality in qualitative research is an ongoing discussion. The four broad principles underpinning the approach by Yardley (2000) were used. This included: sensitivity to context, commitment and rigour, coherence and transparency and impact and importance. Also guidelines for appraising the quality of IPA research published by Smith (2011) was closely followed (see part three for a fuller discussion of quality appraisal).

The researcher had carried out extensive reading on both the quantitative and qualitative literature on the care giving experience of parents of adult children during the earliest stages of the research process and this informed the development of the study aims and methodology. Verbatim extracts from the transcript were included to support the points being made and to ensure that the participant's voice could be heard when reading the analysis. There was a high degree of homogeneity in the participant group to make any subsequent analysis meaningful. Colleagues of the researcher were asked to read the analysis and their feedback was helpful in drawing attention to any section that lacked clarity.

Results

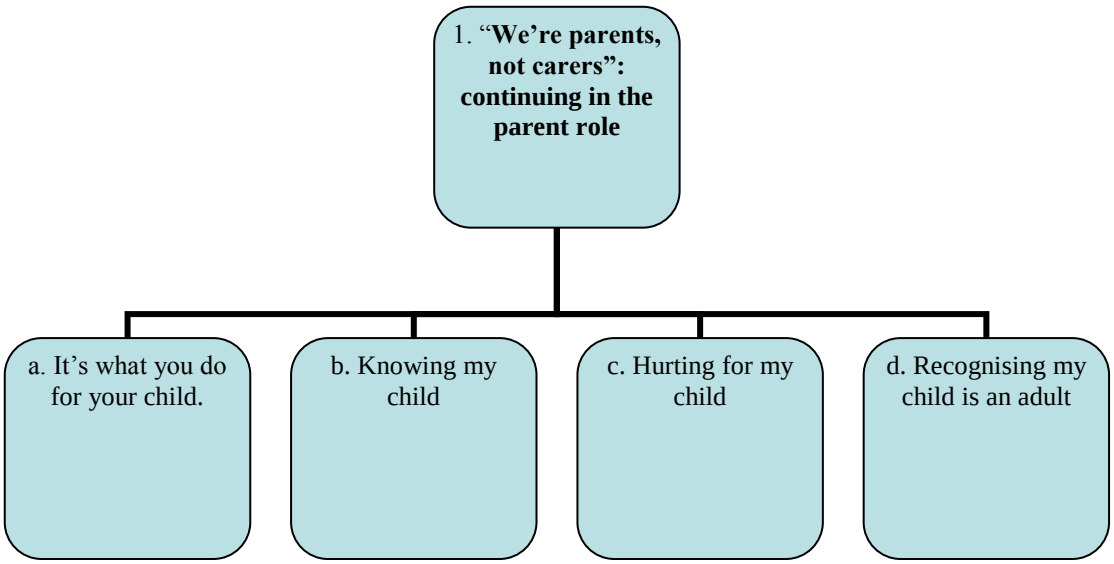
The aim of this study was to explore the lived experience of parents who care for their adult children who have suffered a severe TBI during the first four to six weeks at home after discharge from hospital. Four superordinate themes emerged from the data:

1. "We're parents, not carers": Carrying on with the parenting role;
2. "Being a parent is not enough": Barriers to care giving;
3. "We knew we could do it": Factors that engender mastery;
4. "Life is on hold": The psychological, physical and social impact on parents.

Extracts from participant interviews were used to illustrate subordinate themes in order to allow the voice of the participants to be "heard" throughout the analysis, and to keep the analysis grounded in the data. Superordinate themes are discussed in relation to subordinate themes and reflect at times the seeming contradictions inherent in the participants' sense making of their experiences.

1. "We're parents, not carers" Continuing in the parenting role

The participants in this study identified themselves as mothers (n=5), or the father (n=1), of their adult children, not as carers of patients with a severe TBI. They had all suffered the experience of seeing their children sustain life-threatening injuries and had wondered whether they would live or die. Their children had been in hospital for weeks or months and were now at home and the participants had assumed the responsibility of supporting them in their rehabilitation journey. This is examined in relation to four subordinate themes:



a. It's what you do for your child

For all of the participants there was no question of whether or not they would assume the role of primary caregiver when their son or daughter was discharged from hospital. Each one saw it as natural and right. All but one of the adult children (Anna) had lived in the parental home prior to injury although they had attended college or employment. One of them (Roddy) was in the process of moving out into his own flat, but when he had his accident he moved back into the family home:

"Maybe it's easier in a way for mothers as they're still always your children, no matter what age. And he's such a home bird, always was. We used to say we'd pay him to leave! No, this is his home and he needs some normality in his life" (Kate, 153-157)

For Kate there was no question of Roddy going anywhere else. She wanted normality for him, and that meant being in his family home. Kate thought of herself as Roddy's mother, not his carer. This view resonated with other participants:

"'Carers' is a strong word. I, I don't really see myself as that – or as James needing a 'carer'. I'm his mother, not his carer." (Meg, 461-462)

Meg saw her role as a continuing one, not as one that had to be assumed as a consequence of the accident. Her description of "carer" as a "strong word" implies discomfort with it. She may not have wanted to see herself as a carer/care giver as that would mean a change in her identity from being a mother, and a change in James's identity from son to patient, or person needing care. This discomfort with the term was echoed in Beth's interview:

"He hates the word 'carers'... but that doesn't reflect on what my situation is. I'm his mum. It's what you do for your child." (Beth, 116-118)

It is of interest that while Donald was nineteen years old at the time of the accident his mother still used the word "child". Age was not a factor for the parents as Flora explained:

"*All I wanted to do was sit at my son's bedside from when he woke up in the morning until he went to sleep at night. He needs his mother. It doesn't matter what age he is." (Flora, 190-193)*

Parenting, from the participants' experience, was both "who you are" and "what you do". They all identified with being a parent in the biological sense but also in what that role involved. Flora, on reflecting on her experience of the first few weeks at home, said that she would have taken a more proactive role in maintaining her son's contact with friends and said that, "it's parenting again". She explained that it was about having to do what you did when the children were younger, such as inviting classmates round to tea. Implicit in this is that they had returned to a more intensive, earlier form of parenting.

b. *Knowing my child*

This subordinate theme describes the way in which the parents were sensitive to and attuned to their sons/daughters' needs and mental states. It also reflects an uncertainty regarding whether their sons/daughter were the same people they were before the injuries:

"Of course he's also thinking, 'They're all back at uni and snowboarding and going out. I'm left behind and they've forgotten me.' Of course Face Book doesn't help. They're all posting photos of nights out and he's stuck here. Facebook is a mixed blessing" (Flora, 301-305)

Rona also was aware of the attunement between mother and child:

"You just know, don't you, what's going on. Well, maybe not always" (Rona, 320-322)

Paradoxically, parents also voiced fears that they did not know exactly who had come home from hospital. This is illustrated by Beth's comment:

"Before the accident he was just so, so full of mischief… such good fun. I look at him and wonder, where's the old Donald?" (Beth, 42-45)

At this point Beth was wondering where her "old", pre-injury Donald was. This was a recurring theme during Beth's interview and although she said at various points that Donald was making progress, there was a sense of sadness, as if grieving for the son she used to have. She was not alone in questioning her son's identity. Others also voiced such thoughts:

"We think we have more or less got the same boy back from before the accident but I don't know if his friends see it that way. I know it can take a long time, and we're thinking in years and not weeks and months" (Flora, 41-45)

There was acknowledgement that there may be still be differences between the pre - and post - accident son, but she could also see the "old" son in the post accident one:

"He's getting stronger. He's more like his old self, and his old self is a fighter" (Flora, 345-346)

The use of the present tense in describing "his old self" suggests a continuity of who her son is, which is in contrast to Beth's experience. Hassan did not question whether his son was the same or different on his return home from hospital. He said, *"But you*

know, that's my son." There was no ambivalence and was a sense that they had "picked up from where they had left off." At the same time, Hassan was aware that consequences of TBI could be long lasting and may not have happened at this stage. He talked about the possibility of Ahmed experiencing mood changes which he had been warned about by the rehabilitation team:

"But that's brain injury you know. It hasn't happened yet, but they said it might" (Hassan, 156-157)

c. *Hurting for my child*

Hurting for their adult children was an experience shared by all the participants. The memories of being informed of the accidents were still vivid; although they had occurred weeks or months before, and their children had survived and were now at home:

"Well he was just in a coma, you know , out of his mind, and what could I do, just pray to God you know, and he helped me. Just to see him like that and I couldn't do a thing" (Hassan, 34-36)

This extract illustrates the pain and helplessness Hassan experienced as a parent. He could not spare Ahmed the suffering and could only pray. He had to look on as others took control and could not do what parents want to do; protect their children. All participants went through a time of not knowing whether their children would survive their injuries. Then followed a long time of waiting to see what damage had been

done and what kind of lives their children might have. For Meg it was still difficult to think about what had happened and what could lie ahead:

"Now and again I get a bit weepy, not for me...but for him…what he's gone through (cries). He's still got a long way to go though….He's getting there, that's the main thing. I don't think he realises yet what he's been through yet. He's seen all the pictures and the scars but I don't think he realises" (Meg, 286-292)

Beth shared these concerns and worried that Donald would not come through such an experience "unscathed" as she put it. "Not knowing" was a recurrent theme in Beth's experience. She knew the physical injuries were healing but the "rest", the potential emotional or mental injuries were more frightening. To her at this point, these types of injuries or consequences could have a bigger impact, not only on Donald's life and identity, but her own. The reference to her faith "*If that's what I'm called to do*" implies a calling to a particular role that would be different from the one she was currently fulfilling.

The participants also had to deal with their children's reactions to their injuries. It was during the first few weeks at home that both parents and their adult children became more aware of deficits:

"She was an extrovert, going at a hundred miles an hour, organising this thing and that…and now…to not be able to read, or look at a book, or process a thought and she's very conscious of that. That's hard for a parent to watch. It's so difficult to watch her struggle and to stand back. And of course I'm the one who gets the fallout.

I suppose that's being her mum, she can maybe vent her frustrations with me. But it's hard. It's harder for her though" (Rona, 450 -459)

Anna, Rona's daughter, had been a bright, talented and independent woman. Now she was back in the parental home and was finding the backwards transition from "adult" to "child" very difficult. Not only did her mother have to see her daughter's unhappiness, she had to deal with her own sense of loss for the pre-injury capable daughter. She was also the one who has to absorb Anna's frustration and anger. Being a parent meant having to be the emotional "sponge" for offspring; absorbing and holding their upset and distress.

d. *Recognising my child is an adult*

All participants referred to their adult children as "child" at some point in their interviews, even although they ranged in age from 19-27 years. The parents all acknowledged that they were dealing with adults, chronologically at least and some experienced a tension between positioning them as children and holding close, or looking ahead and encouraging their independence:

"I'm giving up control...that's what it is (laughs). Aye that's what it is. They're not children anymore, they're adults of their own...yeah the instinct is to…protect, to get the balance, what's the boundary? I've to watch out for that" (Meg, 270-274)

Meg was aware of the tension between acknowledgement that she should treat her son like an adult and wanting to keep him close and safe. Treating him as an adult might expose him to situations she could not control. Parents and young adults can struggle

to negotiate new boundaries, even without a TBI. Beth found it very difficult to let Donald out of her sight. Her instinct was to protect and keep him away from anything that could harm him:

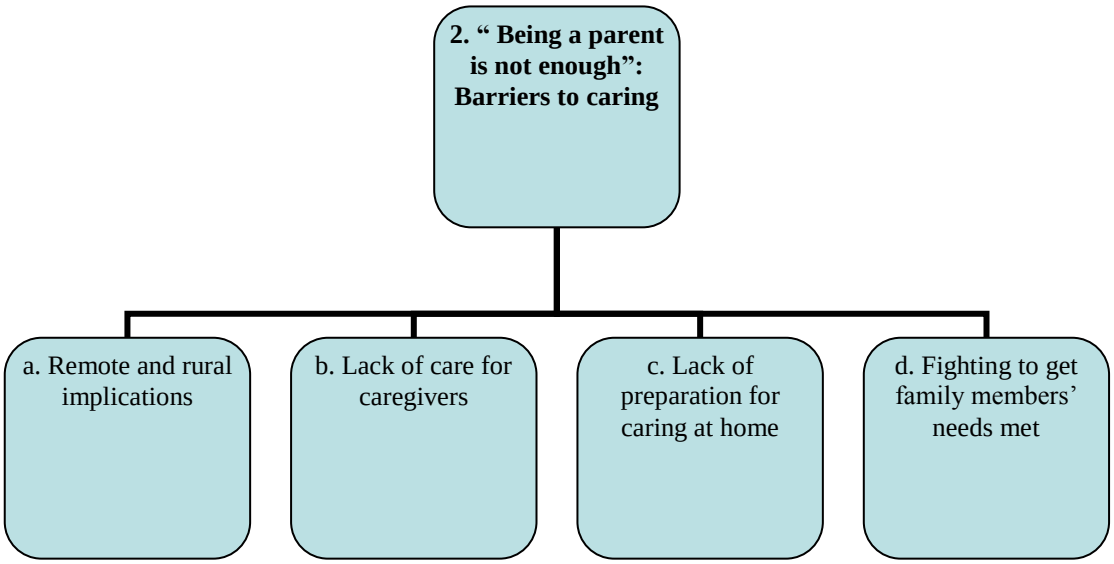
"You know I was hoping, but I don't suppose it's cool for a son to go with his mother, and to go swimming with (girlfriend) rather than his mum and I have to accept that. I suppose, I haven't been able to get the opportunity to do these things with Donald. 'You know you could go in on your own and I could just sit outside'...I suppose I'm just frightened, I don't want to let him go on his own….because I don't know what to expect, will he just all of a sudden, you know, get unwell" (Beth, 91-98)

There was a sense of her wanting to seek proximity to Donald, but he was pulling away from her. She was in a dilemma, not knowing how much to allow him to do. There was also the fact that he was spending more and more time with his girlfriend. Did she resent that, or is it that she was so afraid that something awful would happen to him if she is not there. Beth said later on in the interview that Donald seemed to be striving to be more independent and showing her that he was well and able to do things for himself. However, Donald voiced some ambivalence regarding Beth's protectiveness in complaining to her on one occasion that she had not been there to give him a lift while she had been spending time with her daughter. So both she and Donald had mixed feelings regarding proximity and freedom. It is indicative of how this time frame in the rehabilitation continuum can be unstable and unsettling for the parent and the adult child. Hassan also experienced something of the tension inherent in maintaining a balance between holding close and letting go:

"He's only young, but he has to make decisions too. We can only hope he makes good decisions, and help him to make good decisions. He's not a child any more" (Hassan, 232-234)

2. Being a parent is not enough: Barriers to caregiving

The second super ordinate theme describes the range of factors that made the experience of caregiving more difficult and are reflected in the four subordinate themes. Participants made the point that although they were parents and the caring for their adult child was normal, they were not trained to deal with the abnormal circumstances they found themselves in during the first few weeks at home.



a. *Remote and rural implications*

The participants all lived in a remote and rural area that is the same size as Belgium. They had significant distances to travel during the inpatient period to be with their son or daughter. One participant (Flora) had to stay overseas for her son's acute treatment, as that is where the accident had occurred. The distances travelled had considerable consequences for Meg such as exhaustion, disrupted routines, absence from work,

having to organise care for other family members. Hassan commented that *"Me and the wife were always saying "hello" and goodbye."* while Rona said *"It was hard making the six hour round trip."*

Not only did the participants have to cope with long distances during the inpatient stage, they had to contend with a lack of services in the local community once their adult child had been discharged. They were concerned that any rehabilitation gains made in hospital would be lost as rehabilitation services were either very scarce or non-existent. Kate's experience was shared by other participants:

"There's nothing really for the likes of Roddy. It's not as if he has a learning disability. There's going to be a lot of others in Roddy's boat the way they speed around here. You can't blame them. There's only the pub for young people and that's not good. There is not the staff either. There's no more speech and language or physio." (Kate, 337-341)

Participants commented on the fact that most people with brain injury are young people and yet there were no facilities that reflected their differing needs, for example from stroke patients, who are usually older. The future needs of their family members were a source of anxiety. Although participants wanted to look ahead and move on, the lack of appropriate services was a challenge to them achieving this. Flora thought that her son might benefit from living in another area where there was increased access to services.

b. ***Lack of care for caregivers***

Although the participants' primary concerns focused on the needs of their sons or daughter, five out of the six participants voiced feelings of abandonment at this stage of their journey. Hassan was the exception; he was full of praise for staff in that they not only looked after Ahmed, but they showed Hassan and his wife compassion and respect. This was not the experience of the other participants throughout their contact with professionals in in-patient and outpatient settings. Flora's experience of care for her son and themselves once they had returned from abroad was shocking and disappointing:

"They (staff abroad) seemed to have a clue about what we were experiencing. Well that didn't last long once we got back to Scotland! We had a long flight and when we arrived at [name] hospital we were absolutely exhausted. We could hardly speak. We never even got a cup of tea! I hadn't been home for 4 months" (Flora, 150-155)

When they returned to Scotland the ethos was very different. They were shown little in the way of compassion for themselves or for John. The effect of this was that she felt compelled to stay with him constantly to make sure that his needs were met. The staff in the hospital overseas understood their need to stay close to John; more than that, it was expected. The staff also acknowledged that his parents would be continuing in the role of rehabilitators once John was eventually discharged from hospital. Because of this, Flora was involved in all his therapy sessions. Her knowledge of John was treated as a valuable resource by the medical team when they were developing his rehabilitation programme. Other participants commented on the lack of understanding of the seriousness of TBI and the shock and trauma the

participants had experienced. Because of this there was a sense that their suffering and needs were invisible:

"When people see us they see Roddy and how he's getting on, but no-one asks how we're getting on" (Kate, 401-402)

"I go down town and I meet folk and they ask how I am and I just can't…I'm good at keeping a mask on. 'You look so well, and Donald is dong so well'. You might look ok on the outside but on the inside you're not. No one seems to understand what you go through" (Beth, 236-240)

Kate's comment implied that she and her husband were invisible to others. Their needs were subsumed by Roddy's needs. Beth experienced ambivalence between "keeping a mask on" to hide from others what she was really feeling, and the lack of understanding by others of what her life was like after Donald's accident. This lack of care for care-givers is connected to the following sub ordinate theme, lack of preparation for the care-giving role.

c. *Lack of preparation for care-giving at home*

All participants assumed the care of their child on discharge from hospital, but there was very little in the way of preparation for that role. Hassan was the only participant who did not voice concerns about the discharge process, or their ability as a family to cope at home. This divergent account of the first few weeks at home is useful in demonstrating the contrast between positive and negative experiences of the discharge process. The transition from hospital to home for the other participants was not so

smooth i.e. it was not a collaborative process between professionals and family, and in some cases it happened unexpectedly. Participants found that being a parent was not enough preparation or training to tackle the more specialised challenges of meeting the needs of those who had sustained a TBI:

"I'm not a professional. I can give her all the support, all the mother-love, I can do everything for her but I don't know how to deal with her professionally. I don't know how much she should be doing, how much I should be pushing her, I'm not a trained person" (Rona, 33- 40)

All participants (apart from Hassan) voiced concerns that gains made in the in-patient rehabilitation phase would be lost because they did not know how to maintain them at home:

"I think I feel a bit abandoned now by physios and others – great the first 2-3 weeks, but nothing now and I think, am I able to help him maintain the gains he has made?. So I do feel a bit, a bit, out of my depth. Being a parent isn't enough. You need more than, em, and I used to be a nurse, so how do others feel up here? And discharge was quick, very quick, so you do feel a bit abandoned" (Flora, 333-339)

The above extract highlights how vulnerable participants could feel once their family members were home again. Not even Meg's nurse training was enough to prepare her for the role. It was perhaps Beth who experienced the most unease:

"I panicked when they said he was getting home. I'm too scared to wish he's not going to be left with any scarring, scathed by the injury…I'm not a professional". (Beth, 122-129)

Beth panicked. She was not prepared. Donald had spent some nights at home before final discharge but she and the other participants had not been involved in the planning. Flora had said that being a parent was not enough. There is an impression that the discharge home was something that happened *to* them rather than *with* them.

The other participants may have had some anxiety, but when asked about their family member coming home, their responses were couched in positive terms. Kate's son Roddy had been in hospital for some time and discharge had been delayed because necessary equipment had not been installed in their house. She knew Roddy was frustrated and bored sharing a ward with older people *"who didn't know the time or day so there was absolutely no stimulation as they had no staff anyway who knew about brain injury".* The lack of preparation for the carer role at home was therefore made worse by poor funding and planning.

d. ***Fighting to get family members' needs met***

Unfortunately, the majority of the participants experienced obstacles that were both energy sapping and demoralising. In the interviews they used terms such as "fighting" and "battling" to overcome hurdles. For some, the battle to access appropriate services began during the inpatient period:

"By that time I didn't care what they thought of me. As long as John got what he needed. It's not that I'm one of these people who expect the impossible; I've been a nurse and I know what it's like to deal with the relatives from Hell" (Flora, 223-227)

Flora had found that not only did she feel that the hospital staff in the Scottish brain injury unit failed to show any compassion towards the family; they did not appear to be willing to give John the rehabilitation she thought was appropriate. This led to a breakdown in her relationship with staff; it also led to a lack of trust, which meant she was not confident in leaving the hospital. Kate's experience was similar in that she needed to be present all the time because she was worried about Roddy's safety.

For some participants it was once the adult children had been discharged from hospital that their "battles" commenced. Beth was angry that her son was not receiving what she thought he needed when he left hospital:

"*Well they phoned up the hospital about OT here and they said they didn't know if he was getting OT. I was kind of angry. I just don't want these things dismissed, he's had them up til now and I don't want them to stop now that he's home. So what am I supposed to do? Like...or support him, you know, stimulate his brain to get it back on track…I think…well every mother would want the best for their child…. And I've always done that and that I'll fight…. I think, well, he needs more stimulation but there's no-one to ask" (Beth, 160-166)*

This extract echoes the earlier subordinate theme where a lack of preparation and training to carry on the role of rehabilitator had a significant effect on the well-being

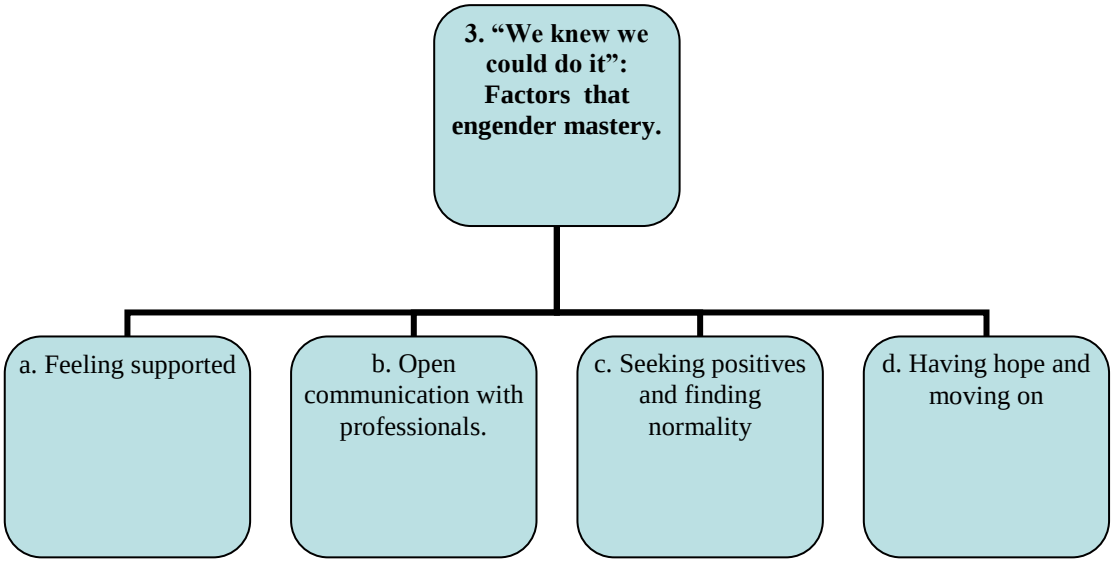
of some participants. Meg, Rona and Beth described the first few weeks at home as very tiring, and Flora had used the term "vulnerable" to describe her state. They were tired, traumatised and faced with many challenges and yet still had to "fight" to get their children's needs met. The following quote from Kate captures the sense of the physical and mental effort required:

"We've had to shout for everything, to fight for what he needs. It gets you down. I have been very low, but I've always managed to pull myself out of it. I have to. He depends on me, and (husband) is struggling himself so I can't be depressed" (Kate, 405-410)

Although the majority of participants experienced a lack of care for themselves, preparation for the task of maintaining rehabilitation gains and lack of services, they also all talked about support they had received from a variety of sources which enabled them to carry on and experience a sense of coping and mastery.

3. Factors Engendering Mastery

All participants reported some positive aspects to caring for their adult children. Each one was grateful that their adult child had survived, and that weeks or months later were well enough to be discharged from hospital.



a. ***Feeling supported***

Support manifested itself in many forms at different points throughout the participants' experiences. Other family members, friends, caring staff, open lines of communication and understanding employers all played an important part in enabling and supporting the participants in this study. Hassan's interview in particular was suffused with gratitude to God, his family, staff and friends:

"I just took my hope to God and He…gave me the strength" (Hassan, 16)

"They see me at the bus stop as I'm not driving, and they give me a lift, so everyone has been helpful. Every day 'How are you getting on?' And so amazing – over a thousand people praying for him when he was in the coma. It was just amazing." (Hassan, 77-81)

This extract indicates that Hassan was carried spiritually and physically throughout the period since the accident. Friends also appreciated that the whole family were

affected. Hassan attributed Ahmed's survival to God and the hospital staff, which may have alleviated the strain he felt as a father. He had experienced helplessness when Ahmed was in a coma, but he handed that helplessness over to a power beyond himself. A spiritual faith had also helped Beth and she was grateful to the church community for helping in practical ways too. Meg was not a religious person but the beliefs of another mother in the intensive care ward had encouraged her:

"We shared a room in ITU with a couple from Northern Ireland whose son had been in an accident two days before. She came in one day and gave me a wee drop holy oil for James and I thought – do you know what, I don't care – if it works, great. She was brilliant"(Meg, 410-414)

Friends and family were a huge source of comfort. Kate recounted how friends in the village had given them money to cover transport costs when they visited Roddy in hospital. Sometimes kindness took participants by surprise, as shown in the following extract from Flora:

"I was overwhelmed and vulnerable. It was the other staff really, the cleaners and assistants, who were supportive and kept me going. It was just showing some kindness, offering me a cup of tea and asking how we were coping"

Flora's experience of nursing and medical care for her son had been very mixed. The care shown to them overseas was very different to the care received in Scotland.

Feeling supported was enabling; it helped to motivate participants to carry on. One participant noticed how she and her husband coped in different but complimentary ways. When she found a particular situation difficult, such as keeping in touch with family with news during the acute stage of treatment, he assumed responsibility for that task. Kate also benefitted from the support of her husband: that she and her husband had *"been together for a long time, donkeys' really"* For the researcher this implied a sense of their stability and togetherness. They had a shared history and the consequences of the accident would be shared together. This sentiment was reflected in Hassan's description of him and his wife as "a team".

In this participant group it did not necessarily follow that having a spouse was seen as a source of support. Beth and Rona both spoke about an inability to speak to their husbands as they did not feel understood, or that their efforts to look after their children were unappreciated.

b. *Open communication with professionals*

Open communication was very important to participants throughout the inpatient and outpatient experience. A sudden and terrifying event had launched them into an alien environment:

"The hospital was great…you know in intensive care they'd tell you what they were doing and that…like...washing his face and getting us to help if we wanted…you know sometimes too much information. But Dr D at the start wanted to know how much, how to play it. We'd decided to get the whole lot thrown at us" (Meg, 78-87)

Meg and her husband were informed and involved from the very beginning. Hassan was confident that his son was receiving excellent care and he, as his father, was shown respect:

"The nurses and doctors were really good at telling us anything and it was really nice to…so you know…they took photos you know of the operations for the students and had my permission…the first person with that sort of injury they saw and they wanted to teach the students. That was good for me" (Hassan, 27-32)

For participants the efforts of professionals to keep communication open was as important as the content of information. They appreciated that medical staff could not provide accurate prognoses, but they needed to have contact with an informed person who would at least tell them what was going on. Not having such contact was detrimental to participants:

"I know they were busy but even if they had just arranged a time when we could speak to someone and find out what was going to happen. I knew they weren't going to say "Well, he'll wake up tomorrow afternoon", but just some idea – or even if they said they didn't know but were keeping a close eye on him. "Well, how long is a piece of string?" is the only answer we ever got" (Kate, 248-253)

Kate's experience reflects how staff can get it wrong. Lack of communication was also seen as a lack of care and sensitivity towards family members at a very difficult time. Sometimes information could be hard to hear. Beth's doctor told them shortly after the accident that Donald could be a different person to the one he was before:

"Then I always remember Dr X who was very good at his job, but his bedside manner was, well, pretty awful, and he said, he just turned to and said 'Well, don't expect Donald to be the boy he was before he came in' And that kind of really floored me" (Beth, 164-169)

The way in which information is communicated is important. Beth's concerns at the time of interview had been affected by this exchange with the consultant; who is Donald, is he the same or different?

Once their adult children were discharged there was a sense of abandonment in that participants had little opportunity to speak to people about brain injury. Rona was surprised by the lack of communication between professionals responsible for Anna's care. Two weeks after discharge Anna had become unwell and Rona was very distressed. Her GP had come across to her as uninformed and disinterested when she phoned for advice:

"If it hadn't been for him (doctor in A & E) we don't know what would have happened. They kept her in overnight and he got in touch with Y hospital and he got copies of her notes and he was just absolutely wonderful. The others hadn't kept in touch, there seemed to be no communication between the hospitals and this GP" (Rona, 88-93)

Meg and Kate commented that although their GPs were supportive, they did not know much about TBI. The participants wanted and needed access to TBI-specific support, and there was very little of that available.

c. *Seeking for positives and finding normality*

Although participants had been traumatised by their children's injuries, each one managed to find some positive outcomes and glimpses of normality. The discharge process had been less than smooth for some but the fact that their children were able to come home was a cause for celebration. Participants relished, for a short time at least, the family being together again:

"So when we came home we could relax and just enjoy, being a family, being normal if you know what I mean" (Flora, 292-296)

"Then it calmed down quite a lot and on the Saturday night we just sat down and watched a film like a normal Saturday night and that was great" (Meg, 200-202)

The experience of "normal" was significant because the participants were reassured to know that they still could experience some normality. Kate had reflected on what had happened and was not tortured by thoughts of blame or resentment:

"We don't bear any grudges. It was a pure accident. They were coming home from work and so there was no drink involved…The other boy had to get surgery on his head too but he's ok now. But accidents happen. In a way we're lucky because he is still here and we're able to look after him at home in his own house. He could have been a lot worse." (Kate, 377- 382)

Kate's attitude of non-blame and ability to be thankful that Roddy survived may have helped her to live with the "new normal." Of all the injured adult children, Roddy was

the one who had suffered the most severe and lasting injuries, yet Kate could still see the positives in her situation. Resilience and ability to cope were expressed by Hassan also:

"I am a coping person, it's personality. It was a miracle. Not all are so fortunate. Our family are not too bad at the moment, you know he still has trouble walking but it's still early days…and there's time to get better even more, so we are very lucky. (Hassan, 99-102)

The above quote encapsulates Hassan's outlook and attributions. He identified himself as someone who copes; he was grateful that Ahmed had survived; his family was close; he had some knowledge of brain injury in that improvement is always possible and he considered the family to be fortunate.

d. Having hope and moving forwards

Hope was thought to be necessary by all participants in order to keep them from "going under" as one put it. They needed hope in order to comfort, encourage and motivate their children to move on:

"They said it was a severe injury and didn't know how things would go, but I've stopped counting the days now – I think I've come on! At first I could only think in days rather than weeks because it was all so uncertain. He was in a coma not all that long ago…amazing. Yeah, I think we're going to be OK. You need hope I think." (Meg 487-493)

Meg summed up the experience of the other participants in recognising the part hope played in their ability to come through their ordeal. Hope was important throughout the inpatient and outpatient period. At the beginning they could not allow themselves to think that their children would die, or stay in a coma; that there would be no betterment for them and that the situation they were in would never improve. Flora explained what a lack of hope would have meant for her:

"You've got to see the positives amongst it all. You've got to have hope. I think without it we would have, probably, gone under. It takes the wind out of you, the accident, and you can't let it drag you down" (Flora, 357-359)

Kate needed hope in order to instil hope in her son. It also helped her see the improvement in her son. In contrast, Beth wanted to hope but was too afraid to in case her worst fears were realised:

"*You try to hope, but you're too scared to get your hopes up. I look at photos of Donald before he had the accident... (tears)... and I just want my boy back. No-one else sees that, says that. I wonder, am I seeing things worse? Am I looking too deep? I don't know, I just don't know" (Beth, 20- 24)*

Beth's inability to hope was painful for her. It was as if the accident had robbed her of the ability to be hopeful or optimistic. It had also robbed her of the son she used to have and the relationship they had shared. Making sense of what had happened was difficult as was trying to make sense of her own thoughts and feelings.

Participants all thought about the future and how to enable their children to progress. These goals ranged from thinking about possible returns to college, to helping one adult child use an iPad as independently as he could. Some participants planned at the more immediate level, such as encouraging someone to eat more healthily or take more responsibility for personal hygiene and taking medication. What was common to all was a desire to help their children move on from where they were at the time of interview:

"We've been thinking ahead. We have to start planning the future, I suppose, as we can't carry on this way for too long. We've got…he's got a place at X college, and we can defer that if he needs to. He thinks he wants to give it a go, so we've been in touch with X (tutor)." (Meg, 403-407)

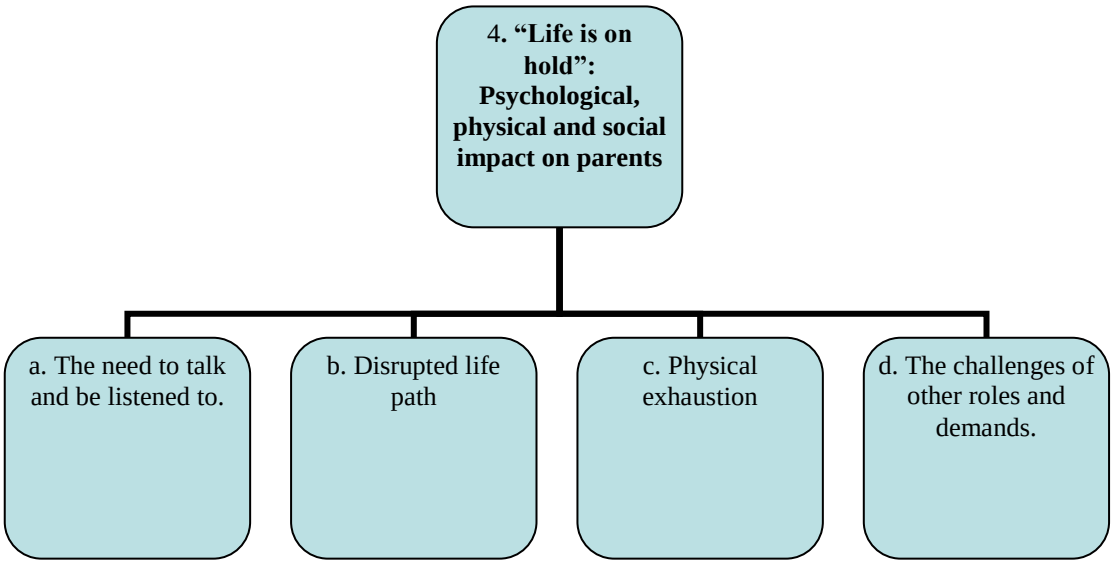
Beth tried to give Donald structure and routine. Some participants looked further ahead and this was perhaps most pertinent to Kate and her husband who were older parents:

"The future is a worry. We're not always going to be around. Who's going to look after him? He has his brothers but they have their own lives. You don't think you're going to have these worries at our age. It's usually what do you do with the parents (laughs)" (Kate, 325-329)

Kate reflected on the disrupting effect of TBI, which changed the natural order of things in their family.

4. "Life is on Hold": Psychological, Physical and Social Impact on Parents

The fourth and final super ordinate theme captures something of the effect of the trauma on the lives of the participants. It was clear that the memories of the early days of the accidents were vivid and distressing for them. They were surprised how emotional they were talking about their experiences. This included Hassan who, on the whole, appeared so positive and philosophical about Ahmed's progress at the time of interview. Participants could all see progress in their children, but some were still very emotionally labile and fragile, and perceived that no-one else understood what they were going through.



a. The need to talk and be listened to

Meg's reflections on her experience since James' discharge showed that even the participants who were optimistic about the future found the first few weeks at home challenging. It was a time when parents' feelings came to the surface and this was at times beyond their control:

"I'm usually ok, it's just talking about it...(nose blowing). To be honest, at the beginning I was fine because you've got family and, em, everyone else to look out for and you're on automatic pilot you know…..oh I'm being pathetic" (Meg, 27-32)

Rona's words echoed Meg's: *"I just don't understand my own emotions just now" (Rona, 9-13)*

During the inpatient period the participants were in "coping mode" as Kate described it. Others talked about the "adrenalin rush" keeping them going and then "running on empty" once they were home. It was now that the emotions that had been kept in check were bubbling to the surface, out of control. Other people were uncomfortable with this so participants did not have an outlet for their worries:

"It's been hard with, I don't think my husband knows why I'm finding it so hard. If I get upset then he goes out or goes all quiet, so I tend to keep my thoughts to myself. Even my sister thinks I'm going overboard on the worrying. Of course she doesn't have kids so it's hard maybe for her to, to, understand how a mother feels. (Rona, 334-39)

b. ***Disrupted life path: Life on hold***

The accidents had suddenly disrupted the lives of the participants and their injured children. The children were all in the process of leaving, or had left the parental home, and were asserting their independence and autonomy. The participants were conscious of moving on to the next stage of their lives. Because of the accidents the planned

futures of participants and young adults had been changed dramatically and they struggled with their new circumstances to varying degrees:

"Life has stopped, well, on hold, to see what happens. I was so naïve about brain injury. We didn't have a clue, still don't have a clue. Right now I feel as if life is on hold and I'm stuck in this place" (Rona, 341-344)

The above extract from Rona's transcript reflected the sense that for themselves and their family members, life was different, on hold, diverted from their expected paths. For Rona, she was stuck in place she did not like, with no directions showing the way out. Not only was life on hold, but going backwards as Meg commented:

"Yes – put things on hold just now and it's back to where we were, doing things that James can get some stimulation from too" (Meg, 73-75)

Meg had also said that she and her husband were just starting to see themselves as a couple. Because of the accident, that new identity was also put "on hold". Kate and her husband had planned activities together but "*That's all gone now*."

Participants commented that their lives were on a different path, but it was more distressing for them to watch their adult children try to come to terms with their new reality:

"But I think he sees himself as a different person almost… that his life is not going the way he wanted it to. That's hard when you're 18 and you were just getting things

together, going out into the world, studying and having a future in…but we have to help him see that life is maybe different, but not stopped. That's what we feel too. We have to. It's just not the life he had planned. It's a difficult adjustment and that's not going to happen overnight" (Flora, 356-362)

Participants had to deal with both their children's distress about the unwanted change in direction, and their own. This load had to be carried at a time when participants had already experienced months of uncertainty and anxiety since the accidents.

c. *Physical Exhaustion*

At the time of interview the participants had all been under a lot of stress and anxiety for months, and the intensity of their exhaustion took them by surprise:

"We were just so dog-tired, like no other tired. I'm just so drained I think, so exhausted. It's all adrenalin and worrying is he going to live then what sort of living will it be and then it's hospital world and trying to keep things as normal as possible for (daughter) and now it's, gosh, I'm weary of it all. I think the body is just saying stop" (Flora, 352-357)

Flora's extract summed up the experience of the other participants vividly. The exhaustion was overwhelming. The first few weeks at home had been described as a time when participants experienced emotional turmoil, as thoughts and feelings surfaced out with their control, and it was also the time that the physical demands they had been under for a prolonged period of time took their toll: "*You're just so wiped out, mentally and physically" (Rona, 256-262).*

That is the backdrop against which they had to deal with other demands and responsibilities, which is the final subordinate theme.

d. *The challenges of other roles and demands*

One participant had described the inpatient period as "living in a bubble". Once their adult child had been discharged from hospital, other responsibilities and demands arose. Work was one; fortunately, their employers did not put most of the participants under pressure directly, but they imposed pressure on themselves by worrying about when they could return and not wanting to inconvenience colleagues. More significant was the sense of guilt experienced by some regarding other family members. Beth felt guilty because her daughter had felt "left out" during her brother's injury and rehabilitation:

"My daughter says she's just not part of the family ……she feels left out and had to endure a lot on her own, em…She's applying for 6th year and...och...she has to attend regularly, not be late and she's saying 'I won't get in.' I've been letting her down and I feel bad about it" (Beth, 209-213)

Beth was experiencing guilt. By trying to be a good mother to Donald, she had been a bad mother to her daughter. She was pulled in different directions. Kate took on the responsibility of trying to protect her husband because she thought he had "taken it worse". She therefore could not afford to be depressed or unwell. Rona had to consider where her main responsibilities lay once Anna came home. Rona decided that she could not leave her and had to deal with the thought that she may have to give

up her work. Rona's future was therefore not her own. In contrast, Hassan was pleased to get the chance to look after his other children:

"My wife and oldest daughter took care of everything when, at first we were both... so she stayed and looked after the others. Now I can be a father to them all and sleep in my own bed so life is good just now" (Hassan, 146-149)

Discussion

The aim of this study was to explore the experience of parents caring for their adult children who had sustained a TBI, with particular reference to the first four to six weeks after discharge from hospital. This was a time when participants experienced a variety of emotions. Their child coming home was anticipated eagerly as well as apprehensively. Although participants were delighted to take their children home, they experienced uncertainty, fatigue, unexpected emotions and unforeseen challenges. They also relished moments of normality when they could all enjoy being together as a family. Although the researcher had asked questions about the first four to six weeks since discharge, participants referred back often to the inpatient period. Turner, Fleming, Cornwell, Worrall, Ownsworth, Haines et al. (2007) had found that their participants described transition from hospital to home as being embedded in the rehabilitation continuum including both the acute and post acute inpatient phase.

Analysis of the data produced four superordinate themes that reflect the experience of the parents caring for their adult children during the first four to six weeks at home: (1) "We're parents, not carers": Carrying on with the parenting role; (2) "Being a

parent is not enough": Barriers to care giving; (3) "We knew we could do it": Factors that engender mastery, and (4) "Life is on hold": The psychological, physical and social impact on parents. Reflections on each theme will discussed with reference to the relevant literature. There will follow a discussion of clinical implications, ideas for future research and finally a consideration of methodological strengths and limitations.

1. "We're parents, not carers": Carrying on with the parenting role

Participants in this study assumed the role of caregiver once their child had been discharged from hospital without question; not that they been given a choice. None of them had received a carer assessment prior to discharge. Participants saw the task as a natural part of being a parent and professional staff appeared to hold this belief too. This is reflected in other research (Carson, 1993; Knight, Devereaux & Godfrey, 1998). Some parents in the current study voiced unease with the term "carer" or "caregiver", perhaps because it implied a change in their own status from "mother" to "carer" which would further imply that the reality and extent of the injuries might be greater than they could accept. This has not been made explicit in other research as far as the researcher is aware.

The participants took their children back to the parental home on discharge from hospital as it was seen as providing normality and stability, as well as a base to carry on with rehabilitation. This is in line with findings from other research (Carson, 1993; Wongvatunyu & Porter, 2005), where home environment was one that could be adapted to meet the physical needs of their children and also where parents could constantly monitor their children's health and safety. The constant monitoring and

proximity to their children harked back to an earlier, more intense form of parenting which is similar to the findings of other researchers (Jumisko, Lexell & Soderberg, 2007; Fumiyo et al., 2009).

The participants in the current study knew their children intimately and were attuned to their needs. They voiced concerns that their expertise as parents was ignored during the inpatient stage, as professionals made decisions about their children without discussion with those who knew them best. Paradoxically it appears that parents' expertise is acknowledged (or taken for granted) post discharge as they are often "left to get on with it" as one participant reported. Only one participant in the current study talked about enjoying a very positive relationship with professionals who had involved the family in decision-making and kept the family informed throughout the inpatient experience. Another had enjoyed such a relationship with staff overseas for a short while, but not in Scotland. Research has shown that care givers who are respected by staff as experts in their own right perceive relationships with professionals as more positive (Lefebvre, Pelchat, Swaine, Gelinas & Levert, 2005). Indeed, caregivers benefit from being treated as colleagues because they have this expert knowledge about their family member, but also as clients because they have their own needs that must be addressed (Van Heugten, Visser-Meily, Post & Lindeman, 2006).

Participants showed that they were attuned to their children's needs but they also wondered whether the children they had known before the accidents were the same ones who came home from hospital. This dilemma is documented in other research where parents wondered who their children were (Carson, 1993; Wongvatunyu &

Porter, 2008a). For some participants, getting to know the "new child" involved a period of grieving for the old, pre-injury child and at the same time searching for the essence of the old child in the new one (Wongvatunyu & Porter, 2008a; Carson, 1993; Knight, Devereaux & Godfrey, 1998; Jumisko et al., 2007).

Seeing their children suffer physically and emotionally was very difficult for all the participants in the current study. Memories of the accidents were vivid although several weeks and months had passed. They suffered with their children, an experience shared by other caregivers (Jumisko et al., 2007). Parents were aware already that their children were being left behind in terms of social interaction and meaningful activity, which has been shown elsewhere (Marsh et al., 2002).

Already at the early stage post discharge parents in the current study were conscious of the difficulty trying to achieve an acceptable balance between keeping safe from further harm and encouraging independence and rehabilitation. Some of the injured adults in the current study found the restrictions on their lifestyles difficult to accept and saw their parents' care as intrusive. This is reflected in the Jones and Morris (2012) study where they found that it was easier for parents to care than it was for adult children to be cared for. All the participants wanted to maintain rehabilitation and promote autonomy but were afraid to take risks and this is reflected in other research (Kao & Stuifbergen, 2004; Wongvatunyu & Porter, 2005). One mother in particular in the current study found it very difficult to accept that her son's romantic partner was playing a significant part in her son's life at the time of interview. There appeared to be a sense of jostling for position as chief caregiver. It may be that other participants did not experience this because their children were not in the same

position. Perhaps the TBI had exacerbated what may have been a tension between mother and son if the accident had not happened. This could be an area of further research.

2. Barriers to care: being a parent is not enough

The participants in the current study all expressed concerns about the lack of post discharge services for their children and for themselves. This was unhelpful at a time when caregivers can be anxious about their family member's discharge (O'Callaghan, McAllister & Wilson, 2011). Distance from TBI specific services had caused problems throughout the period since injury as families had to travel to visit children, or stay away from home. This led to family disruption and exhaustion. Advocacy for their children became a significant part of their experience post accident because there was very little on-going rehabilitation offered by health professionals once they had been discharged from hospital. Becoming an advocate for their children has been reported elsewhere in the parent caregiver literature (Carson, 1993; Kao & Stuifbergen, 2004; Engstrom & Soderberg, 2011). Some participants in the current study experienced "battling" to get needs met during the inpatient and outpatient stage. Turner et al. (2007) highlighted the need for improved access to TBI specific therapy services at this time, and recommended that a case manager should be available to help caregivers to access services.

The idea that caring for the adult child is "what a mother does", as one participant in the current study stated, is echoed in other research (Wongvatunyu & Porter, 2008b; Fumiyo et al., 2009). Jones and Morris (2012) had stated that mothers adjusted well to the caregiving role because that is what they had been used to. In this study the

experience of mothers (and father) was that while it was natural, it was not necessarily easy. There is perhaps a belief that parental caregivers are therefore less in need of support than other caregiver groups, but research has shown that parents do not experience any less distress than spouses for instance, but rather they experience different stresses (Ennis et al., 2012). The participants in the current study did not feel that simply being a parent equipped them for the role they found themselves in because they were being asked to meet needs out with the limits of normal parenting. They were parents, but "not professionals". Some researchers have said that parents felt able to meet their child's needs because it came naturally to them (Wongvatunyu & Porter, 2008a), but the current participants would have liked more training and preparation for coming home, even although two of them were professional carers and one was a trained nurse.

Turner et al. (2007) found that participants who had positive thoughts about the discharge process felt better prepared to cope when they returned home. They stated that the transition phase is an important period worthy of further research as it is a time when both survivors and care givers begin to realise more clearly the significance of consequences of TBI, and a time when care givers can experience depression and anxiety. Participants in the current study had received varying amounts of information about TBI. Some still knew very little about TBI and its consequences at discharge. Seeking answers had become a way of life and this resonates with other research (Smith & Smith, 2000; Rotondi et al., 2007; Brereton & Nolan, 2002). The results of a study by Mackenzie, Perry, Lockhart, Cottee, Cloud and Mann (2007) suggested that discharge planning, and information on caring and sign-posting to appropriate services could prevent some of the problems caregivers

faced further down the line. Brereton and Nolan (2002) pointed out that information is important, but it seemed that the carers had to be proactive in seeking it out, at a time when they were stressed and worried about their loved one, as well as taking care of other responsibilities.

3. Factors Engendering Mastery

All the participants in the current study acknowledged various sources of support, which helped them greatly to deal with their new circumstances. Support came in different forms from different sources. Social support has been recognised as a protective factor against depression, anger and irritability (Ergh, Rapport, Coleman & Hawkes, 2002). Because of the all-consuming nature of care giving it is important that caregivers do not become isolated and their own needs subsumed under the weight of caregiving. This is consistent with the findings of Buschenfeld, Morris and Lockwood (2009). The injured person was the important one, and the carer seemed to become less significant, disappearing from view. This is important as it could mean that carers become less and less able to utilise supports that are available. They may stop engaging in pleasurable activities and may reduce their social interaction, thus becoming vulnerable to stress and mental health problems such as depression.

Open communication with professionals was valued by those who received it. Many parents talked of having questions that no one could answer and they needed information to help them make sense of what was happening. This has been the experience of caregivers elsewhere (Murray, Maslany & Jeffery, 2006). Participants appreciated honesty and were aware that professionals did not always know what was happening, but it was important that professionals were visible and accessible. Other

research has indicated that looking for answers and not getting them is common (Minnes, Woodford, Carlson, Johnston & McColl, 2010). Although hospital staff cannot provide certain information, for example, regarding prognosis, it is important to provide timely information given in an understandable way. It has been found to help families cope during these traumatic times (Verhaeghe, Defloor & Grypdonck, 2005; Verhaeghe, Defloor, van Zuuren, Duijnstee & Grypdonck, 2005; Verhaeghe, van Zuuren, Defloor, Duijnstee & Grypdonck, 2007).

It has been reported elsewhere that participants actively seek positives in their new situation (Kao & Stuifbergen 2004). A study by Machamer, Temken and Dikman (2002) looked at various aspects of caring with 180 family members of those who had suffered a moderate to severe TBI. Participants were interviewed six months after injury. Sixty percent found the experience of caring to be more positive than negative. Ninety-three percent were happy that they had the opportunity to care, and were reasonably confident in their ability to care at least some of the time. Although a large sample, this should be interpreted cautiously as the participants were still at a relatively early stage of the caring journey and perhaps the tools used were not sensitive to all the different aspects of caring. However, such findings are replicated in other research (e.g. Wells, Dywan and Dumas, 2005). Wells at al. (2005) found that those who had a strong sense of their ability to cope were more likely to feel positively about the role of carer.

Participants stated that hope was a very important aspect of coping with their new circumstances. It helped them deal with difficult realities and motivated them to look forwards rather than backwards. Sometimes professionals painted a black picture of

what parents could expect in terms of prognoses, but they continued to hope in spite of that. This is reflected in other research where hope is seen as a defence mechanism (Smith & Smith, 2000; Kao & Stuifbergen, 2004; Engstrom & Soderberg, 2011). However, not all participants were able to hope. Beth was afraid to hope in case her worst fears became reality, which seemed to focus on her son being permanently damaged emotionally by his experience.

4. "Life is on Hold": Psychological, Physical and Social Impact on Parents

Jumisko, Lexell and Soderberg (2007) emphasised the need for professionals to understand the suffering of relatives as this aspect of TBI can be overlooked. The participants in the current study had all been through a terrible ordeal. Some had said that they did not have an opportunity to talk about it as others did not understand, or they did not want to burden others. The period after discharge was one characterised by the surfacing of intense emotions and this surprised them. All participants commented to the researcher that having a chance to talk openly and reflect on their experiences had been very helpful. Perhaps there is a misconception that because the participants were all married and living with their spouses that they would be able to share their worries and concerns. For two participants in the current study this was not the case. Kao and Stuifbergen (2004) talked of "marital menace" where parents' relationships were adversely affected by the demands of caring for the injured child. Jones and Morris (2012) reported that participants dealt with their situation in different ways, which led to distance and lack of intimacy.

The occurrence of the TBI had changed the expected life path of the families, perhaps forever. The young adults were asserting their independence and loosening ties with

their parents. The parents were moving on to a new stage in their lives where some were beginning to identify as a couple again. Others had plans to travel or retire. One participant in the current study was older than the other participants and her husband was in his late sixties with poor health. Her concerns about a disrupted life path were different in that she was concerned about her son's welfare when she and her husband died. This has been found in research concerning older parents who care for an adult child (Minnes, Woodford, Carlson, Johnston & McColl, 2010). Minnes et al. (2010) found that their greatest concerns focused on accommodation for their child and TBI specific information.

Participants voiced surprise at the level of physical and mental exhaustion they experienced during the first few weeks at home. This in part could have been caused by the perceived necessity to be on stand – by constantly while seeing to needs of other family members. Relationships suffered which has been shown elsewhere (Buschenfeld et al., 2009). Participants had also spent the past few weeks and months dealing with the shock of the accidents and the long distance travel and disruption to family routines. Two of the participants in particular experienced psychological distress in the first few weeks at home. One had been prescribed anti-depressant medication, yet none of the participants had been assessed for psychological problems. A study by Pelmeier, Walder, Rebetez and Maercker (2011) found that out of 69 relatives of individuals with TBI, over half had exhibited clinical levels of post-traumatic stress symptoms in the weeks following the accidents. Gillen, Tennen, Affleck and Steinpreis (1998) recommended screening caregivers at the acute stage of the patient's journey, as caregivers do not come to the role as a "blank slate" (Davis, Sander, Struchen, Sherer, Nakase-Richardson & Malec, 2009). They may have had

experience of mental health problems before which could impact on their ability to care. If caregivers were given training in coping strategies, psychoeducation, problem-solving, or carer group interventions then perhaps some of the problems faced by those in this study and elsewhere could be alleviated, both in the short and long term (Verhaeghe et al., 2005) Carers can experience burden and distress as early as three months after injury and up to seven years later (Davis et al., 2009).

The current study examined the experiences of a highly homogeneous group and although the sample size was small, the consistency of findings suggests that they are significant. However, there may have been bias in the recruitment sample due to professionals on the multi-disciplinary team not wanting to approach potential participants they thought may have been too distressed or challenged to take part. This could have led to the exclusion of the data derived from their experience of caregiving. Staff may also have avoided approaching parents with whom they did not have a good relationship. Another important factor to note is that the participant group were not altogether representative of the caregiver population in that although the injured children were predominantly male and in the 18-30 age group, they did not come from socially deprived backgrounds with lower socio economic status and educational opportunity. There was no alcohol or substance misuse involved in the injury contexts and all the families were in employment (ABI Managed Clinical Network, 2009). Therefore the results of this study should be interpreted in the above context and that they are not necessarily a reflection of parent caregivers' experiences across different contexts.

Implications for clinical practice

The findings from the current study add to the literature base on the experience of caring for adult children in general, and during the early period post discharge from hospital in particular. The findings corroborate other research that characterises the particular time frame as an anxious, yet exciting time (Turner et al., 2007; 2011). This study highlights that the discharge from hospital is a significant event in the rehabilitation continuum for both parents and adult children. The interviews with parents showed that their care giving experience started in the acute stage and not just on discharge from hospital. It also highlighted that parents needed support from the very beginning. The experiences of the participants in this study make interesting reading for anyone working with this carer population, whether they are auditing their existing service provision, or setting up a new brain injury service, so therefore this a valuable piece of applied research.

Parents need to be close to their adult children and should not be made by staff to feel as if they are intruding. Staff training, delivered by a clinical psychologist or neuropsychologist, as part of the multi-disciplinary team, could cover areas such as parents' need for proximity and reassurance that their children are receiving the best care. If staff can make sympathetic attributions about parents' behaviour, it may lessen tension between the two groups. Clinical psychologists could highlight the need for staff to include family members at therapy sessions during staff continuing professional development. This study has highlighted again that open and honest communication is helpful to parents throughout their experience and not just in the acute stage.

Parents can be used as an important resource as they know their children better than anyone else. They also want to know that their child is being treated with dignity and respect and this can be achieved by listening to parents and involving them in treatment decisions. This is not a new finding, but this study helps to confirm that when it happens, it could play a significant part in successful communication and positive relationships. It may be particularly significant at the point of discharge when the parent takes over the responsibility of caring from the professionals. It may be that staff members already think that they do the above, but most of the participants in this study perceived that this did not happen. It is important at this stage that carers are assessed to see if they are able to take on the role and what type of support needs to be set up to enable them to care at home, taking into consideration their physical and psychological health. Psychologists are well placed to monitor caregivers' mental health, as well as raise these issues with other members of staff.

Ideally, as discharge from hospital approaches and parents have already been given timely and sensitive information about their children's prognosis (by the psychologist perhaps) and been involved in therapy sessions, parents would be met by members of the multi-disciplinary team. The multi-disciplinary team would discuss the planned time span which should include some "practice runs" at home. This would build parents' confidence and highlight any equipment that would need to be in place for their children returning home. The appointed caseworker would act as a point of contact in and out of hospital if parents had queries regarding the continuation of therapy at home, benefits, meaningful occupation for the children and respite for the

parents if required. The clinical psychologist would be available to provide TBI specific psycho education and counselling if required to any family members.

Parents at discharge should have access to TBI specific information for as long as necessary. Ideally at this stage they should be made aware that the transition from hospital to home can be challenging because it can be when the reality of their children's new circumstances can affect them all. Again this is a part the Clinical Psychologist can play in monitoring parents for signs of stress or depression. It has been shown from this study that even the apparently robust participants described themselves as vulnerable and exhausted.

The exhaustion that parent caregivers can experience has not been highlighted to the same extent as it has in this study. This is an important factor to take into consideration when the TBI survivor is discharged home. The parents in the current study had been under significant stress for the weeks and months preceding discharge. There should be efforts made to ensure that the caregivers are physically able to take on the responsibility, and strategies put in place such as respite or professional carers if required. The study thereforehas implications for other professional groups working with this population. At outpatient appointments the findings could inform rehabilitation consultants'or neurologists' conversations with caregivers such as "I know that some people I see find this time very tiring, and they can feel overwhelmed." This would allow caregivers to discuss feelings they may feel ashamed of when they may feel under pressure to be grateful and positive. The medical staff could take advice from or refer the caregiver to psychology. The findings of this and other qualitative studies can further enhance professionals'

understandings of the trauma this population has been through. This study highlighted that parents need specific input post discharge. That could be in the form of appointments for caregivers themselves on a regular basis. The current participants were told on discharge that their adult child would be seen for a first appointment at a follow-up clinic one to three months post discharge. Because of what other research as well as this study has shown, caregivers need a safe space where they can talk about their own physical and mental health. Ongoing monitoring of their situation should be routine, where an informed professional can ask them about a variety of topics which would allow participants to discuss difficult topics in privacy. At a local level as a result of this study, the researcher will be meeting with caregivers separately from their family members at a newly established ABI clinic. This could be particularly important to caregivers in a remote and rural area because of geographical isolation which has implications for many parts of the UK.

The study has shown that being a parent is not enough to equip people to care for their children in extraordinary circumstances such as the aftermath of TBI. Professionals may assume that because the caregivers are parents "doing what parents do" may belittle the difficulties they face. Clinical Psychologists could explore with staff what being a parent means in terms of their need to seek proximity with their injured child, even if that "child" is an adult.

Finally, this study has also shown that there are positive aspects to caregiving. The participants were able to experience closeness as a family and return to some sense of, although different, normality. Throughout their experience hope played a significant part in enabling them to continue in their role and their belief in that doing so would

also help engender hope in their child and the future. Clinical psychologists can raise awareness of this with other staff, particularly how the way information is conveyed can effect hopefulness.

Future research

The majority of participants in this study were mothers. It may be that fathers have different caring styles, responsibilities and needs. Research into the caregiving experience of fathers would be beneficial as it is an under-researched area. This would add to the rather limited research carried out on gender differences in caregiving. It would also be important to interview participants at different time points as other research has suggested that needs change over time (Turner et al., 2007) and this could be useful to examine future needs. In addition, the present research suggested the possibility of cultural differences, although with such a small sample size it would be inappropriate to make strong inferences about this. Others have noted that there is little research done on other cultures/ethnicities (Jones & Morris, 2012).

A further area for exploration relates to the differences experienced by participants from rural and urban settings, as other research looking at remote and rural implications have been based outside the UK.

The results of this study showed that having a spouse or partner is not necessarily a source of support. Two mothers commented on the lack of understanding and support fro their husbands. All participants in this study were married and it would be useful to look at the experience of lone caregivers. There has been research done looking at

the effects of ABI in spousal relationships (Hunt & Smith, 2004; Buschenfeld et al., 2009) but little on the impact of caregiving in this population.

Participants in the current study commented on the lack of appropriate information on TBI. Useful qualitative research could involve exploring further the experience of staff as they try to equip caregivers with appropriate knowledge, in particular any perceived barriers to sharing that knowledge.

The transition period has been shown to be complex for caregivers as they try to come to terms with their new reality. Two participants in this study displayed signs of psychological distress at the time of discharge. It would be useful to know how aware rehabilitation staff are of the possible consequences of caregiving; whether they could detect psychological distress and what to do about it. Staff training, facilitated by a Clinical Psychologist, could be of benefit as participants in this study commented on the lack of TBI specific knowledge shown by hospital staff.

Strengths and limitations

The research process was guided by the recommendations of Smith et al. (2009) as the researcher was a novice to this type of research and in order to enhance methodological rigour the researcher kept a reflective diary throughout the process and discussed the analysis process with an experienced qualitative researcher.

The use of a qualitative method has enhanced and developed the understanding of the experience of this significant caregiver population. As far as the researcher is aware, this is the first study that has focused specifically on the experience of parent

caregivers of adult children with severe, closed TBI at this particular point in the rehabilitation continuum. It is the first study to use IPA in a study of this population at this time point, thus helping to fill a gap in the research literature.

The participants were interviewed shortly after their adult children were discharged from hospital so they were not depending on retrospective memory. The use of IPA enabled the gathering of data that reflected the complexities of participants' experiences that quantitative methods would have been unable to do.

The participant group was smaller than the researcher would have liked but the population was hard to reach, but still within the recommended sample size (Smith et al., 2009). Purposive sampling allowed for the recruitment of a homogeneous group that would substantiate the findings. Participation in the research was voluntary and some potential participants (n=3) initially expressed interest but did not commit to the research. Their experiences could have added further insight into the caregiving experience, and knowing why they did not want to continue would be interesting. However, the high level of homogeneity in the group allowed for a detailed analysis which contributes to the applied research base on the experience of caregiving for adult children with TBI.

Conclusion

This study has added to the existing literature as it is the first study, as far as the researcher is aware, that focused on this particular population at this particular time point on the rehabilitation journey after TBI. The findings have both resonated with other research on the experience of parent caregivers and highlighted the findings that

being a parent does not automatically equip a person to deal with the abnormal demands made on them when an adult child sustains a TBI. Parents may not experience role change in the same way as spouses might do, but in their continuing role as parent to their adult child, they have to take on responsibility for rehabilitation, advocacy, and encouraging their adult child to be as independent as they can be. This is significant as there may be a perception that parents do not need the support that other carer groups do. The study shows that while it is important to know the different needs of different caregiver groups, the question regarding who faces the most difficulty, parents or spouses, is unhelpful as it implies that one group is not so in need of support as another. In current times, when health boards face difficult financial decisions, it may be that support for the "less needy" group may be withheld. This study has highlighted that even the most able parents (some were trained nurses or carers) were in need of support and that this should be in place from the start of the parents' journey. Although the first few weeks at home were exciting and marked an important milestone in the family experience, all the parents were physically and mentally exhausted A significant novel finding in this study is that parents do not see a change in their identity: they are first and foremost parents, not carers. However they all had to deal with events that are outside of the expected experience of parenting an adult child. The study findings can inform staff training relating to the needs of parents from the acute stage onwards. The study also makes more explicit the need for clinicians to work collaboratively with parents and take a proactive role in preparing parents for the first few weeks at home.

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PART III

METHODOLOGY, QUALITY & REFLECTIONS

Reflections on Methodology and Quality

The first part of this chapter will focus on the methodology used in the empirical project and an appraisal of the project. The second part will consist of a reflection on the research process itself which includes extracts from a reflective diary.

Methodology

A qualitative design was used in this project as the aim was to explore the meanings participants made of a particular phenomenon. A qualitative, rather than a quantitative, design was chosen because the aim of the study was not to identify cause and effect relationships between processes that are observable and measurable, but to explore the meanings that individuals make of their experience of a particular phenomenon. A number of qualitative methods were considered in order to decide which method would be most appropriate to examining the area of interest. The most common used in psychological research are Grounded Theory, Discourse Analysis and Interpretative Phenomenological Analysis (IPA) (Harper, 2013). These methods share commonalities such as data gathering methods and an intensive interpretative analysis but they differ in terms of their philosophical roots and end products (Starks & Brown-Trinidad, 2007). Discourse Analysis is concerned with how language is used in achieving personal and social projects (Starks & Brown –Trinidad, 2007), and the function of language in particular contexts (Reid, Flowers & Larkin, 2005) or how individuals construct their social reality (Willig, 2001). Grounded Theory's roots (Glaser & Strauss, 1967) developed in Sociology and researchers aim to generate theory from a range of participants' experiences when seeking explanatory models from which they can develop interventions (Starks & Brown-Trinidad, 2007). It aims

to develop an explanatory theory of social processes, a theoretical-level account of the phenomenon in question (Starks & Brown-Trinidad, 2007; Smith, Flowers & Larkin, 2009).

IPA is suited to exploring how individuals make sense of their experiences and acknowledge the part played by emotion and cognition. Smith (1996) wrote that IPA allows researchers to untangle meanings through the process of interpretation. As the researcher's interest did not lie in studying the language used to describe experiences or to produce an exploratory model of a process, IPA was chosen as the most appropriate method in which to explore participants' perceptions and beliefs about their experience as caregivers of adult children with a severe TBI. This would be useful in helping professionals to understand the views of service users and enable them to integrate research and practice. IPA can provide valuable insights into the experiences of those who are going to be the recipients of care services; it gives a "voice" to those who are directly affected by the decisions made by professionals and service developers. As Reid, Flowers and Larkin (2005) pointed out; IPA may be a popular choice of method within health psychology in particular because it can extend understanding the bio-psycho-social perspectives and encourage listening to what service users need.

IPA's theoretical roots can be found in phenomenology, hermeneutics and idiography (Smith, 2011). Phenomenology is concerned with the exploration of a person's experience (Husserl, 1925), their subjective reality depends on how they make sense of or consciously reflect on their experiences to derive meaning (Larkin, Watts & Clifton, 2006; Willig, 2001). An IPA study can never achieve an objective first hand

account as the account is a co-construction between the participant and researcher (Larkin et al., 2006), so the aim is to get as close to the participant's experience as possible. In IPA research the researcher is involved in what Smith called a "double hermeneutic" (Smith, 2011), in which the researcher tries to make sense of the participants' sense-making. It is important to acknowledge this double hermeneutic and reflect on this in the analysis of the data (Smith, Flowers & Larkin, 2009) as any sense-making by the researcher is made through his or her "interpretative lens" (Willig, 2001). Smith (2011) acknowledged that one person can never really enter the mind of another, but by carefully recording, transcribing and interpretative engagement with the transcripts of the interviews, some sense of the essence of that individual's experience can be achieved.

Quality issues

Quality in Qualitative Research

Yardley (2000) suggested a number of principles that should be adhered to in order to produce good qualitative research and these principles are drawn on by Smith et al. (2009). These are: sensitivity to context; commitment and rigour; transparency and coherence; impact and importance. Further guidance on achieving quality regarding IPA research in particular was provided by Smith (2011).

Sensitivity to context

One way of showing sensitivity to context (Yardley, 2000) is acknowledging "the interactional nature of data collection" (Smith et al., 2009, p180). As Smith et al. (2009) pointed out; a sound analysis is dependent on the availability of good data, so the interactional skills of the researcher are paramount. The researcher listened empathically

to participants and also tried to address some possible power imbalances between interviewer and interviewee. Participants were reminded that they were the experts in the interview and that issues significant to them would be the focus of discussion. There may have been some awkwardness for participants talking about service provision as the researcher was an NHS employee.

Sensitivity can be seen to be present if the reader can hear the voice of the participants in the study. The current researcher was able to draw on interviewing skills developed in working clinically with potentially vulnerable populations. Reference was made to the participants' words throughout the analysis and the idiographic stance was strengthened by highlighting convergences and divergences in the transcripts. An auditable trail was presented of the data collection and analysis process. An awareness of the existing literature on the experience of parental caregivers also shows sensitivity to context.

Commitment and rigour

Smith et al. (2009, p181) wrote that "rigour refers to the thoroughness of the study, for example in terms of the appropriateness of the sample to the question in hand, the quality of the interview and the completeness of the analysis undertaken." The researcher had read carefully the relevant literature and the participant group was homogeneous in order to make findings more meaningful. Undertaking a study using IPA demands commitment from the researcher in that in order to gain meaningful data, the researcher has to listen and attend very carefully to the participants' perspectives and then carry out a careful and insightful interpretation of that material This involves moving beyond simply describing what the participants said and onto producing an interpretation of what they meant, at an individual level and across cases. This interpretation must be corroborated by extracts from the transcripts and the researcher included carefully chosen extracts from across the

participant group. The analysis was discussed with an academic supervisor with extensive qualitative research experience. Colleagues also read the study to ensure clarity. Respondent validation checks were carried out with two participants.

Transparency and coherence

Transparency was achieved by providing enough methodological and analytical detail so that another researcher could repeat the study. An auditable trail was provided which included extracts from the analysis stage, supporting extracts from the transcripts as well as tables containing themes and frequency. Another way of enhancing transparency and coherence used was through reflecting on the impact of the researcher's experience, background, knowledge and motives on the research process (Yardley, 2000).

Impact and importance

Impact and importance refers to the contribution of the current findings to theoretical knowledge and application to clinical practice. For Yardley (2000) this is the bench mark by which any piece of research should be measured. The current research has important clinical implications for clinicians in terms of enhancing their understanding of the experience of parents caring for their adult child with TBI and with recommendations about how that knowledge can improve their clinical practice. The study also extends the knowledge base regarding the first few weeks at home when responsibility shifts from professional staff to parents. This has been recognised as a significant transition for both parents and their adult children. The researcher hopes to publish the study findings and to present the study at a local health board research conference. The researcher has already been able to incorporate findings into her own clinical practice with ABI survivors and caregivers. She is also involved with

developing improved ABI services which will include greater emphasis on support for caregivers.

The Yardley quality criteria above could be applied to a variety of qualitative approaches. Smith (2011) questioned whether a "one-size-fits–all" approach is appropriate or should individual approaches have tailor made criteria. In his paper on the contribution of IPA he presented a guide as to what good IPA should look like. The researcher applied this to her own project.

Smith (2011) made the following statements regarding quality. A good IPA paper should have a clear focus; strong data; rigorous methodology; appropriate elaboration of each theme; an interpretative analysis rather than pure description; should point to both convergence and divergence and be carefully written.

The current study has a clear focus in that it explores the experience of a small, homogenous group at a particular time. The interviews provided rich data that allowed for a detailed analysis. The analysis followed closely the step by step guidelines provided by Smith et al. (2009). There were ample extracts used to capture the essence of themes that illustrated how participants' could experience that theme in different ways. Extracts were used from at least half the participant group to support each theme and frequency of themes was provided for the group as a whole. All participants were represented rather than focusing on one or two. The researcher aimed to write a clear account of the participants' experiences and colleagues read various sections and provided useful feed-back.

The issue of generalisation in qualitative research has been the subject of discussion and it has been pointed out that in the qualitative paradigm, the aim is not on the generalisation of results but the transferability of findings from group to group (Hefferon & Gil-Rodriguez, 2011). In their core text on IPA, Smith et al. (2009) talk about "theoretical generalisability" wherein clinicians can assess the relevance of their findings to their own context based on their existing knowledge and expertise. Smith et al. (2009) continued by commenting that IPA findings are therefore generalised in a more "step-by-step" way. Yardley (2008) contributed to the discussion by differentiating between "horizontal" and "vertical generalisability" IPA findings can enhance understanding and insights and contribute to existing theories and encourage the generation of new hypotheses so this is "vertical generalisability" Horizontal generalisability would be the application of findings across settings. The current study used a smaller participant group than the researcher had planned, but the group were homogeneous on type of relationship, severity of injury, age of injured person, geographical area and circumstances of accidents. Themes were not included if they were not relevant to at least four of the group. The findings from the current study have provided a deeper insight into the experience of a small group, but can be added to the growing body of evidence on this population at this time in the rehabilitation continuum and help to fill a gap in the literature.

Reflections on the Research Process

Smith et al. (2009) recommended that researchers should clearly reflect upon their position within the IPA research process. The following section is written in the first person.

As a novice to qualitative research methods I read widely on the varying methodologies and their theoretical underpinnings. I had decided on the area I wanted to explore for my thesis project, that is, the experience of parents caring for adult children with a brain injury, and concluded that IPA was the most appropriate method. Interpretation is a significant element in IPA and Smith et al. (2009) recommend that a researcher should reflect on his/her own knowledge, beliefs and position in the researcher/participant encounter. A reflective diary was kept throughout the process.

In my role as a trainee clinical psychologist, I spent my third year elective placement on a younger peoples' rehabilitation unit (YARU). Patients were transferred to YARU once their condition had stabilised post surgery in a specialist neurosurgical unit. By the time family members reached us, they were often exhausted and stressed. Although the immediate threat of death had passed, there was always the chance of complications such as infection. The patients were often young men who had been in car accidents. I felt particularly sympathetic towards parents, perhaps because my husband and I had some experience of spending time in hospital with a seriously ill child some years previously. Our experience was relatively short lived with a positive outcome and I wondered how the parents of seriously injured young adults with TBI coped during the many days and weeks they spent in an alien hospital environment.

Talking with family members on the ward further stimulated my interest in research in looking at their experiences in the aftermath of a traumatic brain injury. An anxiety, however, was that asking people about their experiences during a very traumatic time was intrusive. I hoped that by carefully wording information sheets people would

know beforehand what the project would entail for them and that they were under no obligation to take part. I did not approach potential participants myself in case they felt under pressure to take part. I felt reasonably confident that the interview schedule was adequate, but I was nervous about the first interview. I wanted to allow the participant to raise what was important to her and not be constrained by the questions I had set.

That was ok in that she certainly talked a lot, almost as if she was releasing pressure. At times more like a therapy session so must watch for that next time. I'm upset for her that she is struggling so much and not getting any answers or reassurance. What would her son say? Smothering? How hard not to be over-protective. A lot of data in one interview! Too long – cup of tea afterwards maybe encouraged her to treat it as a therapy session especially when she's so desperate to ask questions and find some answers.

It was hard not to be affected by the participants' stories. I came away from two interviews in particular where I worried about their emotional health.

Very fragile. She lives in a house full of people but no-one listens to her. Again, the need to have someone to talk to.

Other interviews left me more optimistic for the future of the caregivers. I was amazed at how people do cope in awful circumstances.

That was a very quick hour! XXXXX has a hardy mother. A strong character – bit scary at first asking questions. The dog certainly helped build rapport. It must be hard taking a stranger into your house and talk about your hopes and fears. They'll be ok I think, the family all pulling together. All have different ways of coping but they compliment each other.

All the participants were very generous with their time. This was a pressure in a way as I wanted to make sure I caught all that was important to them. I found I had not stuck rigidly to the interview schedule at all as each person spoke freely and at length and may have allowed for important matters come up.

I have hours of transcribed material and spent hours with bits of paper with themes and subthemes all over the floor. I feel overwhelmed. I don't want to miss anything important, but don't want to try to include everything. If I only look at themes that most or all of them brought up, is that not moving away from the idiographic thrust of IPA?

However, with practice and supervision I could accommodate the important individual experiences by thinking of them as different experiences of the same theme.

Recruitment was a lengthy process the anxiety regarding that did dampen my enthusiasm for the project at times. However, I was encouraged by the responses of participants. There was no shortage of data and they all commented that participation had been a positive experience for them. It confirmed my growing impression that the chance to talk and be listened to was therapeutic in itself. At times it was difficult as the interviews

progressed not to try and only hear what I wanted to hear, that is, data that would fit neatly into my growing list of themes. Maintaining an awareness of this and discussing it in peer support ensured that this was managed to an extent. Discussion also with my supervisor was encouraging as she could see why I had organised the data in the way I did and helped with questions I had about the validity of what I was doing and "Is this IPA?"

Overall the experience was a steep learning curve. I had no previous experience of IPA research although I had read research papers. The method some how resonates with a psychologist as it allows the interviewer to try and get closer to what someone is thinking and feeling, or as far as anyone can. What I did have, thanks to the teaching and clinical placements, was a chance to develop skills as a listener and an observer. It has made me think of what the researcher brings to an interview situation. I hope it will enhance clinical skills, for example, comfortably tolerating and making use of silences during appointments with patients. I would have lost some valuable data if I had not waited and allowed people to reflect. Overall the experience of taking part appeared to be a positive experience for participants, which was very reassuring for me.

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